

Birchgrove

Issue 1

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Birchgrove - the past, present and future.

For many years I did not really know what Birchgrove was about. I received the newsletter for a long time before I ever got in touch or ever attended an event put on by Birchgrove. My only regret is that I didn't get to know the people I have met through Birchgrove earlier. The reason behind this is the empathic support that I have received. After years of living in isolation and secrecy with HIV I was able to meet and get to know people who shared my experiences, who understood and who made me able to have a laugh at my situation, something that I never thought I would be able to do.

From a chance meeting of Gareth and Paul in the 1980's and a meeting of four people in a pub called "The Birchgrove" the idea of a support group for all people with Haemophilia infected with HIV came about. I would guess that no one at that meeting would have believed that some of us would still be here in 2001. I certainly didn't think I would be. Over the years Birchgrove have supported hundreds of people, have given information and advice, have campaigned for justice, have organized support events where people who are affected can meet and has importantly given people a voice with the newsletter, which in itself has had numerous changes over the years.

The reason there have been so many changes is unfortunately very obvious in that over the years Birchgrove volunteers have become too ill to continue and many have died as a result of their viral infections. This is the nature of the beast and one that we have all had to adapt to however hard it has been.

The whole picture today looks very different than it did in the late 1980's and early 1990's when we all lost so many friends so quickly. The advent of multi anti-HIV drug choices has given hope, the impact of HCV and liver failure has

taken that hope away for many. Treatment issues and the advent of theoretical CJD infection have opened new concerns for some. The social stigma and public attitude to HIV has changed although still far from perfect.

The brick that has supported Birchgrove through these changes has been Gareth who has dedicated most of his life to the causes of people with Haemophilia and has been "Mr. Birchgrove" himself. From first meeting Gareth about three years ago he has made a huge impression on my life and I certainly would not be doing what I am doing today if it wasn't for his encouragement and get up and go. I think I am speaking for the rest of the Birchgrove committee when I say that it is because of Gareth's drive and enthusiasm over the years that we realize that Birchgrove must continue and have a future for those out there that need support, empathy and an opportunity to feel that they are not alone.

As Gareth needs a break at the moment from the workload of Birchgrove we have had to make some changes to ensure that Birchgrove has a future. The postal address has now been changed to Birchgrove PO Box 9755 Solihull B92 9WA and we also have a new E-mail address

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(birchgrove1@hotmail.com). The phone line will still operate on a new number 08457-697231 and messages will be replied to as soon as possible.

If we and Birchgrove are to have a future then it is up to you as readers to help us give this support as well as receive it. It is your stories and experiences about the many aspects of living with HIV that make our group so unique. As people with Haemophilia and HIV, and for most of us HCV co-infection, we have very special and individual needs that only people in the same situation can fully understand. Your experiences of treatments may help another person in their own life choices and decision-making. Your perspectives and coping strategies may help another, or you too may derive benefit from other people's experiences.

Whatever the future holds, Birchgrove is still run by volunteers who have Haemophilia and have been infected with HIV and we know only too well that we are not immortal or superhuman and that there are limits to the service we would like to provide. If you have been affected by the impact of HIV and would like to help us help others please do get in touch. The future of Birchgrove may well be your hands.

Paul

Hat Trick Group

The Hat Trick Group supports all people in London and the South East living with and affected by haemophilia and HIV. This includes family, friends, partners and those who are bereaved.

The group was originally part of the services at Body Positive London and when that organisation had funding withdrawn an individual continued the group on a voluntary and independent basis.

Hat Trick aims to offer peer support to all its members to alleviate the loneliness, isolation and fear they encounter. Support includes helping people access quality information; regular meetings for people to share challenges and experiences including the opportunity for people to get together and meet socially

Although the group is independent of any organisation it is funded by Crusaid and supported in other ways by The Haemophilia Society, THT Lighthouse and The Macfarlane Trust.

The group was set up in the spring of 2000 and works closely with other support organisations within the haemophilia community and beyond. Historically people with haemophilia have not accessed support services from mainstream HIV organisations and the group recognises that members may have challenges that can only be truly understood by people sharing them.

All support is offered in total confidence and on an equal basis to everyone affected.

For further information please contact the following:

- **Richard or Babs on 0800 018 6068**
- **haemophiliagroup@hotmail.com**

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THE Winning FEELING

31st of January 2001, this was the date I received a letter from my Haemophilia unit informing me that on the 10th of December 1996 I had taken home 40 bottles of home treatment that “contained plasma from a blood donor who recently developed new variant CJD”. Having contracted HIV, Hepatitis B, and Hepatitis C and over the last decade being told how safe plasma based factor VIII was I thought I had nothing else to fear, how wrong I was. From that day on I decided I could not sit in silence any longer, I gathered all my Factor VIII put it all in a black bag and returned it to my unit informing them I would not be returning for anymore treatment until they could provide me with the safest form of treatment currently available genetically manufactured Factor VIII (Recombinant) which I later found out could have been made available in 1996.

I returned home and promptly sat down and wrote a letter to my local Health Authority informing them of my actions and requesting that they provide me with funding for Recombinant Factor VIII. I also advised them that I would be on a treatment strike until then.

The next decision I made was one of the hardest and the best decisions I have ever made. Most people new all about my health status, family and friends but we made the decision to be honest and open to all and in doing so I contacted the local press in the hope that this would add some weight to my application to the Health Authorities. Within the space of 2 Months my Local Health Authority had convened a complex case panel, whatever that is, and decided that they would fund my recombinant. I have to say I was a little shocked, as I know of only one other haemophiliac in Britain who has managed to do this and he had to go on a treatment strike for 7 months before his Health Authority gave in.

I have to wonder if the press coverage I received and am still receiving swayed the decision of the panel, or for once did someone in the Health Service actually sit down

and think, yes this is the safest treatment we can provide regardless of cost, yes they do deserve this treatment as we cannot guarantee the safety of the plasma based Factor, and just because he has HIV, Hepatitis B, Hepatitis C and know possibly vCJD this does not mean we can write him off and give the cheapest treatment because he may die soon anyway.

I know that most haemophiliacs feel they could never stand up and tell the world about their status and unfortunately for so long this is what the Health Authorities and the Government have relied upon. I decided to make a stand and have not looked back since. From the moment I became more open I have had support from all areas including family, friends I have even had my local shop keepers come up to me to say they had seen me on the BBC News and they thought it was disgusting and if they could do anything to help I had only to ask.

I realise that most haemophiliacs for their own reasons cannot do what I have done, but until we do the relevant authorities will continue to give us a substandard service and regard us as a waste of money. From the day I stopped hiding in the shadows and started to fight for what I had a right to (even though we shouldn't have to fight for safe treatment) I have never felt better in my self. I am more relaxed and there is no anxiety about what I may or may not say in front of people.

On a more realistic note, for those of you who are thinking of applying to your Health Authority for Recombinant Factor, bear in mind that I still have no Recombinant Factor VIII due to the world shortage and I am still refusing blood based products because for some unknown reason no one will guarantee their safety. I wonder why!

Mick Mason

Extracts of an interview with Dr Janice Main, Senior Lecturer in Infectious Diseases and General medicine at St Mary's Hospital, where Babs Evans, the HIV worker for the Haemophilia Society asks about the affects of hepatitis C (HCV), how and when to treat HIV and HCV and the side effects of drugs.

What are the effects of HCV infection and the first things that people might notice?

If I was to go out and share needles with one of my drug users, nothing might happen, or 6 to 8 weeks later I might get acute hepatitis. I may not notice or I may just feel a little off colour. I may go jaundiced but this is unusual with HCV in that acute stage, unlike hepatitis B (HBV). I might get over it (about 40% of women will get rid of the virus, compared to about 20 % of men) or I might become a chronic carrier.

For those that become chronic carriers, it's a very variable course of chronic liver damage. Generally nothing much happens in the first ten years or the second ten years. It's really into the third decade of the disease that you start to see the serious problems. The people who do less well are men who are older at the time of infection and who drink a lot. There are some people who progress very rapidly, including people with HIV who've got immune system damage.

How do you monitor HCV?

The HCV viral load doesn't seem to tell us very much so it's mainly a case of looking at a patient to see if they've got clinical signs, skin changes or symptoms. Talking to a patient and examining the criteria will give you information about whether the liver is damaged. One of the liver's many functions is as a sort of recycling plant, so if the liver is packing in some of the waste products can build up in the system and we can find that in blood tests.

The gold standard at the moment to find out how bad or good things are is to have a liver biopsy. That tells us two things, how much damage there is at the moment and how far into the disease progression someone is. Often it's good news and they've got very mild liver damage or it might show that they are about to slip into cirrhosis.

So if the liver damage is more severe you would consider treatment?

Yes. If someone knows the facts they might

think 'what are the priorities in my life?' and maybe the priority is to do something about HCV. It's very useful for drug users, as you can't do everything at once. You can't come off alcohol, drugs and sort out your HIV, HCV and everything else, but if you've got mild disease you know that you've got time to sort out the detox. If you've got more severe disease then maybe you've got to think about something else, like maintenance Methadone but get your liver sorted out.

If you've got HIV and HCV it depends on the stages of the disease. Some people had HCV for 20 years and only recently got HIV, for others it's the other way round and some (like people with haemophilia) may have got both a long time ago.

If we've got someone that's very early on in their HIV career it might be better to give them HCV treatment then, whilst their immune system's working and they're not needing HIV drugs. If you're already on HIV drugs with a low CD4 count and you've then to take the HCV drugs, it makes it more of a challenge for the patient and the doctor.

Are there any guidelines for treating HIV and HCV co-infection?

There are US guidelines. In the UK there are guidelines on the management of HCV produced by the Royal College of Physicians of London and the British Society of Gastroenterology. There are the BHIVA (British HIV Association) guidelines for HIV, which are currently being updated.

NICE (National Institute for Clinical Excellence) licensed interferon and ribavirin last year to treat HCV. What is the aim of treatment with these drugs?

The gold standard is to get rid of the virus and hopefully if we do that before the patient develops scarring of the liver then it will regenerate and heal. Even if we can't get rid of the virus the therapy may still help in other ways and recent studies suggest show that you may reduce the chance of developing liver cancer.

I know that ribavirin can cause fetal abnormalities, what other side effects are there with interferon and ribavirin? Interferon can suppress the bone marrow so we have to monitor the blood very carefully to ensure that the white blood cell count doesn't drop. If somebody's on HIV drugs like

zidovudine, for example, that becomes more of a challenge and HIV itself puts a strain on the bone marrow. People often feel, especially in the first week, as if they've got the flu, a bit shivery and achy. Most people feel a lot better by the next week and we try to get round it by taking the interferon at bedtime and taking paracetamol to get through the worst of the side-effects.

Other side-effects can be mild diarrhoea, headaches, hair thinning. A major thing is the depression and we often find that people with no background of depression need to have anti-depressants to help them through the treatment. Usually people manage to come off them once they've got into the course of interferon. There doesn't seem to be any interaction problems like there are with St John's Wart and some of the HIV drugs. Ribavirin increases the destruction of red cells so anaemia is the main problem there. It can cause rashes and the risk of fetal damage.

Often people who have HIV have suffered depression and may have taken anti-depressants - would that rule them out of getting treatment?

You have to weigh up the risks with the benefits. If somebody had major depression or suicidal illness in the past we'd be quite worried and may have to work with a psychiatrist to make sure the treatment is started at the optimum time.

Have you found that employers have generally been sympathetic if people have had to take time off around this treatment? Some people find, especially if they've got a demanding job, that interferon and the job is quite difficult to cope with. Most employers we've dealt with have been sympathetic. We suggest that people have the first week off but some people may find that they are not able to cope well with work and may have to discuss the treatment with their employer.

Is there any difference in the success of treatment in different groups, ethnic origins or gender?

Women seem to do slightly better than men and certain strains of the virus seem harder to treat (Genotype 1 and 4). At the moment we don't have a lot of information about people with HIV. If your CD4 count's a reasonable level your chances are as good or bad as someone who doesn't have HIV. There are

quite a few studies underway at the moment.

Can you take HIV and HCV medication together?

Yes. We just have to be careful about monitoring and do regular liver function tests. A number of HIV drugs can cause liver damage so that would be a worry in someone that already has liver damage with HCV. You would just have to carefully monitor the blood tests.

All the drugs have been implicated, NRTIs, NNRTIs and PIs. I use Nevirapine containing regimens a lot with this group of patients and haven't run into problems.

If someone is having a break from HIV treatment and has HCV would this be a good time to consider treating the HCV?

Yes, although the treatment courses are 6 to 12 months so you'd have to monitor their HIV carefully during that time.

What can you do if a liver is very severely damaged already?

We would monitor someone very carefully and regularly check liver functions. If we thought that the liver was going to fail we would have to consider whether a transplant might be appropriate.

Would having HIV rule you off the transplant list?

No, the results in the early days were really bad if you had HIV but they are a bit better now. It depends on the relative stage of the HIV. If someone is on to his or her 5th combo and the prognosis was not good anyway it might not be appropriate. We have links with transplant units and they have agreed that they will assess our patients and accept them for transplant.

How can someone help his or her liver to stay healthy?

One thing I would say is that people may have been told to go on fat free or other diets but there is no evidence to suggest any reason to do this and people should eat a normal and varied diet. The only thing to watch is alcohol, as this with HCV seems to make the liver damage worse. If somebody has very severe liver damage we would advise him or her to restrict his or her salt intake but that's about it.

(First appeared in Positively Women July/ Aug 2001)

Co-infection Seminar

On the 29th May a one day seminar on HIV and Hepatitis co-infection took place at BMA House, where specialist from the field of HIV, hepatitis, epidemiology, haematology and service users met to discuss treatment and care for co-infected people.

Organised by The Haemophilia Society's HIV worker, Babs Evans, this event was the first of its kind and was designed to facilitate improved knowledge and awareness of the best possible practice amongst health and social care professionals working with people with Co-infection.

During the day there were many speakers and presentations including a number of people with Haemophilia who gave their own accounts of their diverse care experiences.

Also amongst the delegates were dentists, nurses, partners, pharmaceuticals, the press, researchers, social workers and voluntary organizations. Amongst the topics covered were The national survey of provision of care for patients with HIV and hepatitis by Haemophilia centers, the psycho social impact, indications for treatments and latest treatment evidence, side effects of HAART, liver transplantation and developing a co-infection clinic were only some of the topics covered.

A full report of the Seminar will be available by the end of the summer and hopefully will give weight to a more holistic approach to the care of people with Haemophilia trying to fight both viruses at the same time.

There will be an update in the next edition of the Birchgrove newsletter.

The Youth of Today

I am confused. When my friend, fellow triple-H sufferer and co-editor of this newsletter asked me to write a piece for this newsletter, he said something along the lines of: "...we need some fresh ideas – let's get some input from you youngsters for a change instead of us 'olduns' with our stuck-in-the-mud ways..."

I paraphrase, but you get the idea. Now, my friend is 37. The UK Haemophilia Youth Network defines the upper age range for younger people, or 'youths', as being 30. Thus, according to my calculations, middle-age has been reduced to a seven year period, beginning at 30 and ending at 37, when we all officially become 'olduns'. They say that life begins at 40, but by my reckoning we'll all be three years past our best before date by the time the big four-oh comes around. Surely it can't be right that if we reach the grand old age of 75, we will have spent over 50% of our lives as old fogies??

This disturbing scenario raises some obvious questions: is this phenomenon limited to the co-infected haemophilia community; have the government taken this into account when budgeting for the pension fund; the list is endless.

So the older section of our community is getting younger, it seems. Given the nature of our particular group of problems, perhaps this is not unusual. However, I have a theory that this is not the only age-related phenomenon, and to explain it I'll need to tell you a little about myself as one of the 'youngsters'... be warned however that I might get somewhat lost along the way, and most probably contradict my own theory several times, but please bear in mind that at 24 I am only 6 years away from middle-age and as such may well be losing my marbles...

The basis of my theory is formed around the following premise: we as younger people, although sharing the fundamental physical problems that affect pretty much everyone who has cause to read this newsletter, have had to deal with them in different ways. Our social status and time of life were obviously very different when we were infected with our blood-borne nasties – I was just 5 years old – and as such, by the time the effects of the viruses begin to show themselves, we have known nothing other than what it is to be a child. Indeed, the sad fact is that many of us have died never having experienced adulthood.

Those few of us who have survived probably have very similar stories to tell. For me personally, Hepatitis C has not yet been a major problem. HIV however has been affecting me since my early teens, and has had a powerful effect in shaping my life during what for most people would be their most formative years.

I know a few people from our community as a whole who have never told their parents of their HIV+ status; I am different in that there really was no choice in the matter: my mother told me, at age 13 just before starting high-school, that the government had cut one too many corners and given me a deadly disease with no cure. Being 13 years old, and obviously invincible, I was apparently less bothered about it than you might imagine, commenting along the lines that in that case I'd have to become a doctor when I left school, and