

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**

The Hat Trick Group

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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