

# Birchgrove

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## Wise up. Wear it. Where's Yours?

### Birchgrove Website now launched....

This will be the last edition of the Birchgrove newsletter in its current format as the web site has now been launched. This has taken longer than we expected due to scanning the vast amount of text during Birchgrove's history into web readable format. This now means that all the past editions of The Birchgrove will be available to view in one place. It also means that our issues can be brought to a wider audiences attention. Not only do we hope this will embrace our history it will also be a valuable tool to educate and inform others. We are all aware that we did not expect to still be alive today, and responding to our changing needs is an ongoing process. We hope by introducing this website that we can inform people immediately of relevant issues through the website, rather than quarterly via the newsletter. It hasn't been a decision that has been taken lightly, or without consultation as we realise the value of the newsletter to our readers. We would like to take this opportunity to thank everyone involved with Birchgrove since its conception. We would like to thank all the former editors and contributors that have kept this newsletter alive and relevant to our issues. We would like to thank the Haemophilia Society for funding the majority of past issues and The National Lottery-Awards for All for funding the past 4 issues. We would also like to thank all the people that have supported the Birchgrove Woodland Project especially the people that helped fundraise for this worthy cause that has been especially important for many to see this project to completion.

We have no idea how Birchgrove will survive the future, as that is dependant on our health and our changing needs. We hope that it will continue, and that Birchgrove can be a platform for our issues as long as we have them.

Check out [www.birchgrovegroup.org](http://www.birchgrovegroup.org)



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<http://www.birchgrovegroup.org>



# HIV and the Law

After fighting for justice ourselves for nearly 20 years we have faced many hurdles and a roller coaster of emotions. It now seems that for those of us left alive justice has come full circle to put us at risk of being the potential perpetrators of crime, not the recipients.

A number of legal cases over the last couple of years has changed the perception of the law and the transmission of HIV, and the legal responsibilities of people living with HIV.

Although these cases are new to the world of HIV they have been based on the "Offences Against the Person Act 1861" section 20- "recklessly inflicting grievous bodily harm". Transmitting HIV to a sexual partner is now seen by the law as recklessly inflicting grievous bodily harm. (This law will also be used for any other serious transmissible infection- so don't think your Hep C will go unnoticed).

As ignorance of the law offers no defence, this article is aimed to inform people living with HIV exactly what their legal responsibilities are, and what in reality this means to us. Sadly most of it is unclear, as no cases have been won by the person with HIV in court. This means we do not know what a good defence is or could be.

We now, probably, have a legal responsibility to inform sexual partners of our HIV and HCV status? Does this mean that practising safe sex without informing is not enough? Would we still be reckless if a condom burst? Does someone actually have to be infected, or is the act of putting someone at risk punishable by law? If someone agrees to have unsafe sex with us, for example to try and have a child together, can we still be prosecuted? How difficult are cases to prove, as this would be based on one person's word against another? What is actually meant by informing people of your status? How can you prove that you informed them? Does the person with HIV also have to assess the ability of the person they are informing to be able to understand the information and make choices? Is it still reckless and grievous to have sex with someone if you yourself have diminished responsibility through alcohol impairment for example? Can the crime be downgraded to drunk and disorderly? Is their no responsibility of the other person to ask your status before sex, or is it just up to us?

Some ways to avoid the risk of prosecution under the new laws may be to stop having sex or contact with anybody, live on your own on a rock out at sea, have "HIV/HCV Danger Zone" printed on all your underpants or a suitable legal disclaimer tattooed on your genitalia such as "The management take no responsibility for the actions of others with this piece of

equipment".

Ideally, informing people at the right time, in the right setting with someone you trust is preferable to any of the above suggestions. To the majority of Birchgrove readers this has been something that has been problematic since we were infected and informed ourselves. (with apologies to those in Scotland who were not informed until later)

## What is Reckless Transmission?

If someone knows they are HIV positive, and is aware of the transmission risk, and they take an unjustifiable risk that results in the transmission of HIV, they are potentially guilty of recklessly inflicting grievous bodily harm. Enforced by a maximum of 5 years prison for each proven offence.

## What is an unjustifiable Risk?

This is not defined by law, but decided by the jury on each individual case.

## What is Informed Consent?

A valid defence maybe to claim that the person who became infected with HIV consented to the risk of transmission. However, consenting to sex is not the same as consenting to the risk of HIV transmission. This was decided in the Court of Appeal in the recent "Konzani" case. Informed consent is established when the HIV positive person informs the other person of their HIV status.

The National Aids Trust (NAT) have a policy paper on criminalisation, which outlines the current law as follows:

**-You are only likely to be prosecuted for reckless transmission if you have sex with a partner who does not know you are HIV positive and you don't tell them. You must always use a condom, and you must not be infected as a direct result of your decision to make a confession to the police.**

The law at present seems unclear on many aspects, and we may see further developments relating to our legal responsibility. The law at present contradicts the governments sexual health strategy which stresses individual responsibility for sexual health. In Scotland the law is slightly different with Scottish Common Law prosecuting for "culpable and reckless conduct" of transmission of HIV.

Mr Justice Roger Toulson, Chairman of the Law Commission, told BBC's Radio 4 "Unreliable Evidence" programme in May, relating to HIV transmission, "If you pass a really serious disease in a way which is seriously irresponsible, the criminal law should be available there, because it's about protecting the vulnerable".

Most archive readers will agree with Mr Justice Gibson's remarks.

We as venerable NHS patients, from babies to the elderly, were passed a serious message, which many believe was transmitted in a way that was seriously irresponsible, certainly reckless and definitely causing grievous harm.

Unfortunately we haven't had the criminal law available to help us.

As this year's theme to Worlds AIDS Day in the UK is "Wise up, wear it, where's yours?" this is extremely appropriate to the responsibility we face as individuals living with HIV.

#### **Further reading and thanks to**

Edwin J Bernard- "Criminilising HIV Transmission" ATU (NAM) July/Aug 2005 issue 148

[www.tht.org.uk](http://www.tht.org.uk)

NAT Policy—[www.nat.org.uk](http://www.nat.org.uk)

Sigma research produced for CHAPS  
[www.sigmaresearch.org.uk](http://www.sigmaresearch.org.uk)

BHIVA criminilisation guidelines-  
[www.bhiva.org.uk](http://www.bhiva.org.uk)

Scottish information-  
[www.hivscotland.com](http://www.hivscotland.com)

NAM web site- [www.aidsmap.com](http://www.aidsmap.com)

[www.gnpplus.net](http://www.gnpplus.net)- "Criminilisation of HIV transmission in Europe"

## **Haemophilia and HIV transmission in the news**

### **Judge orders HIV man to be locked up**

A HAEMOPHILIAC who infected his girlfriend with the HIV virus has been detained in a psychiatric hospital.

A person living with haemophilia and HIV was originally charged with infecting the woman to the danger of her health and life by culpable and reckless conduct.

The defendant was alleged to have had sex with her between May 1999 and December 2002, knowing or believing he was infected with HIV and knowing it could be transmitted.

It was alleged that he culpably and recklessly and with total disregard for the consequences repeatedly had sex with the woman.

At the hearing, he had been deemed insane and unfit to plead and it was ruled a trial could not proceed.

But, in a rare procedure, an examination of the facts took place, with witnesses called. The court was satisfied beyond reasonable doubt that he had committed the offence and there was no ground for acquittal.

He was held in the psychiatric hospital pending his appearance before Lord Philip at the High Court in Edinburgh, where he made an order requiring him to be placed in medium secure conditions for the immediate future.

**Full Story-**<http://www.eveningtimes.co.uk/print/news/5038698.shtml> Scotland Evening Times May 2005

### **Girl, 20, jailed for infecting boyfriend**

Jul 19 2005 Western Mail <http://icwales.icnetwork.co.uk/0100news/0200wales/tm>

A YOUNG woman yesterday became the first in Britain to be convicted of recklessly infecting her lover with HIV during sex. The woman had sex with the boyfriend for 10 months knowing she was HIV positive.

She was jailed yesterday for two years for unlawfully inflicting grievous bodily harm on her former boyfriend, also 20.

**Daily Mail- Monday July 25th** stated that "the girl is understood to have been herself infected after sleeping with a man who was a haemophiliac and had unknowingly received a contaminated blood transfusion"

# No Freedom of Information

## Haemophiliacs blocked in bid for secret files

Haemophilia and Hepatitis-infected campaigners requesting the release of classified documents under freedom of information legislation have had their demand turned down on the grounds of cost and that they had probably had been destroyed. Peter Mossman, the vice chairman of the Manor House Group, which was formed by haemophiliacs infected with hepatitis C, said he was "appalled" by the failure to release the documents. He said: "I do not believe they have been destroyed. I think it is the biggest cover-up ever. What also appalls me is that they still insist they cannot have a public inquiry- it is just incredible."

see: Sunday Herald 24 April 2005 <http://www.sundayherald.com/49357>

## UKHCDO – Refuse to release records

Dictated by Prof. Hill on 20.09.05.

Dear Mr. Lewis,

The position with regard to access to the past minutes of meetings is UKHCDO is a registered charity and we are advised that the Freedom of Information Act does not apply to the information held by UKHCDO. In addition, it has been estimated the cost of checking and copying UKHCDO archived material will significantly exceed £600. This checking would be essential to ensure that any confidential information (eg. that might identify individual patients) that may form part of these records is identified and removed prior to release in accordance with the Data Protection of 1998. For these reasons UKHCDO have decided not to release their records.

*Yours sincerely,*

*Frank G.H. Hill*

Professor of Paediatric Haematology  
(Chairman - UKHCDO)

## Patients request data

22.9.05

Dear Ms Lynne Dewhurst

I have forwarded this response from the Chairman of the UKHCDO (prof F Hill). As you can see his response gave a few reasons why the minutes from past meetings would not be made available.

If we assume that the cost is not an issue and will be paid in full. this leaves only the matter of the patients named in any data requested, as the data requested concerns meetings between the UKHCDO and the DoH, BTS, and the MHRA or as it was formally known the MRC there would be no mention of patient names within the minutes because of the same reasons given in the Chairmans reply to me (confidential information).

Therefore I can not agree with the excuses stated by the Chairman unless he is admitting that patients are discussed by name at meetings with civil servants and any of the above mentioned independent bodies, which would be in breach of the Data protection act by his own admission within the email reply I received from the Chairman Please can you advise on the process I need to follow to make an official request for data, which I will then provide a more detailed list, when your reply confirms my request will be agreed too.

I Hope the committee agree with this request as the Haemophilia community will only be left with one assumption, that the UKHCDO or for that matter the DoH have legal reasons for not allowing this information into the public domain.

*Your sincerely*  
*Haydn Lewis*



# A Tribute to Peter Longstaff

Peter sadly died on the 16th of April 2005 following a long battle with HIV and Hepatitis C. He remained brave and determined to resist his pain and suffering which he bore with great dignity and fortitude. There are many fellow haemophiliacs like me, who will mourn his passing, because he was a fine example of someone who despite his physical illnesses never became bitter, but generously shared his experiences, his vast knowledge on haemophilia issues, and indeed his sharp wit, which made many people laugh.

I had the privilege of knowing Peter for a number of years, and worked with him on many campaign issues for fellow haemophiliacs infected with multiple viruses. He was generous in his sharing of documents and important information, and was willing to allow people to access his American legal representation to enable them to take part in the current litigation against US pharmaceuticals. I believe many of us owe Peter and his wonderful wife Carol a great debt. I hope those members who knew Peter, will remember him for all the support he and his wife have given the haemophilia community over many years, and that the justice he sought for so long will be continued through the efforts of his fellow haemophiliacs.

*By Colette Wintle*

## **Peter Longstaff**

Peter didn't ask for too much in his life. He wanted the best treatment available, honest answers to his questions and justice.

His tireless campaigning, with the support of Carol, has led to the litigation currently taking place in the USA, as well as highlighting and bringing to the public's attention the realities of living with Haemophilia and HIV/ HCV infection in the UK.

Peter's altruistic decision to leave his body to medical science to help investigate the relation of blood products and CJD may help save some of our lives in the future.

Birchgrove would like to express sympathy to Carol and wish her success in continuing with Peter's fight for justice.

Pete will always be remembered.

## **Peter's fighting on beyond his death**

Apr 19 2005 By Graeme Whitfield, The Journal

A health campaigner who lost his fight for life has made a final contribution to his battle for fellow haemophilia sufferers.

Peter Longstaff, who was infected with HIV and hepatitis C from infected NHS blood transfusions, died at the weekend as he was being taken to St Oswald's Hospice, in Newcastle.

But the 47-year-old, has donated his body to medical science to find out whether he and fellow haemophiliacs have also been infected with CJD.

Mr Longstaff had been told that he had been put at risk from CJD from infected blood transfusions, but there is no test that can be carried out for the disease while people are alive.

It is now hoped that tests can establish whether or not he was infected with the illness.

Mr Longstaff's wife Carol Grayson paid tribute yesterday to his bravery at the end of a long illness. She said: "He was incredibly courageous and he dies as he lived: fighting hard with tremendous courage

"He must have known his chances of making it back to the hospice were slim but he took the chance and it was distressing to be with him in his final minutes.

"Pete had already decided to donate his body to the CJD surveillance unit at Edinburgh.

"A lot of haemophiliacs were exposed to variant CJD and he wanted to establish whether people had been infected or not.

"It must have been very difficult for him to contemplate, but he had the care and the kindness to think that in his death, he could help us learn more about what happened and that other people could benefit from that."

*From IC Newcastle- The Journal*

See other haemophilia related articles that Peter was involved with by visiting:

<http://icwcastle.icnetwork.co.uk/search.cfm?searchscope=50081&query=Haemophilia&num=10&start=0&gobut.x=17&gobut.y=12>

or search for ic Newcastle Journal Haemophilia.

# Blood and Tears

## BBC Scotland-Frontline Scotland

Blood and Tears is a documentary film, which was aired this June on BBC Scotland. The film features people with Haemophilia and HIV in Edinburgh and their fight for the truth behind their infections. The film charts the history of Haemophilia treatments and how HIV and HCV was allowed to contaminate Factor VIII supplies.

Robert explained how he was told it was safe. John said that a risk was never mentioned.

The only recollection either of them had was when Prof. Christopher Ludlum in late 1984 invited a number of his patients to a lecture theatre at the hospital and informed them that "some patients have AIDS, and some have not"

Blood and Tears reported that 18 individual haemophiliacs were infected with HIV in one batch alone.

Robert was one of them, and he was only told 3 years after being infected after becoming ill himself. He also discovered that his Uncles and cousin also had been infected with the virus. His first concerns were for the safety of his wife and child, who he could have unknowingly passed the virus to in the time he was infected but never informed.

When John, who was only informed of his HIV status in 1991, recently received copies of his medical notes, he was shocked to see in November 1984 "Haemophilia AIDS study-High Risk Sample" on his blood results. Patients were being tested for HIV but not informed. Their blood samples were high risk, but the factor they were keeping in their fridge had no such warnings.

On Blood and Tears, Professor Ian Franklin of the Scottish Blood Transfusion Service (BTS) stated that " factor VIII was seen as a life transforming product balanced against Cryo."

Solicitor Raymond Bradley who was involved in Irish litigation stated "that by 1982 there was a known risk of AIDS".

Dr Cees Smit of the Nederlands Haemophilia Society said " All patients were warned and offered alternative treatment, as it was known to the authorities in USA and Europe that there was a potential HIV problem" Dr Smit said that "the authorities should have took all necessary measures to reduce the risk of transmission." The Netherlands in the early 1980's became almost self sufficient in its own donor blood supplies and as a result of more careful donor selection have far fewer incidences of HIV and HCV transmission. Their policy not to use prisons or donors from high-risk groups paid off for their patients.

However in Scotland the Haemophilia Doctors and the BTS discussed the risks of AIDS but decided not to put warnings on factor VIII bottles as it "Could cause patients unnecessary stress". The BTS by 1982 decided also to become self sufficient in Scottish blood supplies as they recognized there was more of a risk with commercial US imported products.

Blood and Tears highlighted the lack of common sense that in the absence of a HIV test in the early 1980's, the only way to ensure that blood products are the safest, is to screen donors for lifestyle risks.

But just as the USA harvested blood from prison donors the Scottish BTS admitted visiting and collecting blood from all the Scottish prisons up to 1984. A 1982 report from Government Inspectors warned the BTS not to take prison blood but the practice took 2 years to stop. Prof. Ian Franklin tried to defend this by saying that demand for the product was high and that the phasing out of using Prisons was a gradual process.

At the same time blood was also being harvested from US naval bases in Scotland from

US sailors even though by this time the USA was seen as the hotbed of AIDS.

Raymond Bradley stated that between '83 and '85 when US plasma donors were known to be a higher risk than European donors that "Scotland was taking a gamble with patient safety"

On top of this, the facilities that produced factor VIII were also under scrutiny as work accelerated beyond the facilities capability. UK Medicines Inspectors reports from the early 1980's states that "erroneous issue from this store has resulted in Hepatitis positive blood being transfused" "Facilities fail to meet minimum standards" together with expired licenses and blood products not kept at correct temperatures.

Raymond Bradley explained that Crown Immunity meant that the BTS were not susceptible to regulation and licensing procedures. However "this was used as a method to avoid proper standards- that was inappropriate"

After 1985 and the identification and testing of the AIDS virus, treatments became safer due to heat-treating of factor products. However in Scotland these products were not heated enough to eradicate HCV. Scottish heat-treated products after 1985 only managed to eradicate HIV.

Bill did not realise this and as a person with mild Haemophilia he had his first treatment of Factor VIII in 1986 in Scotland after a walking accident. Bill contracted hepatitis C with his first and only treatment of Factor VIII and he believes that if he had been treated in an English or Welsh hospital he would have been safe at that time.

Dr Ludlum meanwhile, wrote in a medical journal- **"In Edinburgh we have had the opportunity to study a unique group of haemophiliacs who became infected in Spring of 1984 by transfusion of a single batch of Factor VIII concentrate"**

A 1984 internal advisory document clearly stated that " patients should have been informed, reassured and counseled" according to the film, but Dr Ludlum choose not to inform some of his patients about their HIV status.

Dr Ludlum was asked "Why were your patients not told about their status?" his reply was that " patients were encouraged to make an appointment to see their haemophilia doctor for more information and to discuss their own test results"

The Executive reply was that there is no need for a public inquiry- "We have great sympathy with those affected and their families. The treatment given to haemophiliacs was provided in good faith by the health professionals involved. The risks of that treatment were not known at that time".

[www.bbc.co.uk/frontline](http://www.bbc.co.uk/frontline)

For further information and how to obtain a copy go to  
<http://www.haemophilia.org.uk/hsbb/index.php?action=vthread&forum=5&topic=135>

Or see

[http://news.bbc.co.uk/2/hi/uk\\_news/scotland/4597901.stm](http://news.bbc.co.uk/2/hi/uk_news/scotland/4597901.stm) for story on "Fresh demands for Hep C inquiry"

Birchgrove would like to thank Robert, John and Bill for sharing their experiences through **Blood and Tears** in order to educate a wider audience and promote the need for justice and an inquiry. Stay well.

# HUMAN GIVENS

Authors: Joe Griffin and Ivan Tyrrell - [www.humangivens.com](http://www.humangivens.com)

## A Book Review by Gareth Lewis

Where to start? Firstly Human Givens is not really a book but a way of life ! But then it's the first book I've ever read that you keep going back to for clarification or explanations as to Why ! and How ! certain things or situations have an affect on the way you have dealt with, or deal with them in every walk of life. It gives an insight into how to remain calm and in control. ( And yes I'm still learning both ) but now see things and deal with them in a calmer and rational way, I Hope and Think !

I must go back to the Men Only weekend in May 2004 in Nottingham. You know the one. That's it all the women from the Mac Trust were there ! Got it.

At this weekend I was lucky to sit in on a session called, Don't look back in Anger ? by Mike Beard PhD, and something else that escapes me at the mow. All I will say about that session is, it made me think. It made me take some time when I got home to look at my life, to look at what was making all things happen. So I get on the WEB and order my copy of Human Givens. I read it and will continue to read it for the rest of my life.

So what is this book about. I hear you say ? This book explores and looks at what we all need from life in order to develop well. It looks at how as a society, we are damaging or squandering our natural inheritance. This being our ability to live in a stress free environment. Which has led to rising levels of mental distress, depression, anxiety and psychosis.

'Human Givens' looks at scientific ideas and findings about how the mind works, which helps us to understand how and why we react to certain situations in every day life. It also gives us the tools which enables us to deal with things in an more calming and understanding way. It has shown me how to progress and evolve further, it has made me think and question not only what I do, but why I do it !!

We are all born with physical and emotional needs that must be satisfactorily met if our minds are to develop to their fullest potential. and connect with the world, this book helps us to determine our own individual character, our own and our family's emotional health and happiness.

A lot of what I've read and still reading takes me hours and hours to understand, but with some research and a lot of cross referencing it starts to make sense. And if I can make it work for me then I'm sure the rest of you will have no problems.

This book helps you draw on scientific findings, gathered mainly over the last few decades, about how we human beings function, and refers to our basic emotional needs (such as attention, security, connection and control), and the innate resources we have for meeting them (such as memory, imagination, problem solving abilities and complementary thinking styles). It is when these emotional needs are not met, or our resources are used incorrectly, that individuals suffer mental distress or fail to fulfill their potential.

The book explains how we best approach the psychological pressures of living in our modern world by promoting emotional health and clear thinking. The approach is a new organising idea founded on a solid basis of fundamental research. It is driven by our ever increasing scientific knowledge about human biology, behaviour and psychology and an interest in how best to put such knowledge to practical use.

... gathered  
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## WHAT ARE THE 'HUMAN GIVENS'?

'Human givens' is the term now often used to describe the physical and emotional needs that evolution has programmed into us, together with the resources nature provided, to help us get those needs met. These innate needs seek their fulfillment through the way we interact with the environment using the resources nature has given us.

Our emotional needs include: security (stable home life, privacy and a safe territory to live in); the need for attention (to give and receive it); connection to others through friendship, fun, love, intimacy; a sense of autonomy and control; being part of a wider social community, which satisfies our need to belong; the need for status; a sense of self-competence (that comes through maturity, learning and the application of skills) and a drive for meaning and purpose.

Our resources include: curiosity; long-term memory; imagination (which allows us to focus our attention away from our emotions in order to problem solve more objectively); a dreaming brain; the ability to understand the world and other people and extract deeper meaning through metaphor – pattern matching; an observing self; the ability to empathise and connect with others; a rational mind to check out emotions.

It is these needs and resources, which are built into our biology, that, together, make up the human givens.

It is now widely observed that most problem behaviour and psychological distress can be traced to innate physical and emotional needs not being met, for whatever reason, or to the misuse of a particular innate resource (such as imagination, when it generates worrying, envy, or excessive greed). When they work closely in alignment with the 'givens' of human nature, rather than with techniques derived from limited ideologies, psychotherapists, social workers and teachers are more effective.

In addition, it is increasingly being noted that the human givens framework offers a much-needed larger organising idea to those who wish to make the institutions of law, government and the public services more in tune with the psychobiological reality of human needs.

## THE 'HUMAN GIVENS'

The human givens are our innate physical and emotional needs. These needs are not difficult to appreciate since we all share them. As human animals we are born into a material world where we need air to breathe, water, nutritious food and sufficient of the right quality of sleep. These are our paramount physical needs. Without them, we quickly die – as many people do in parts of the world where clean water is scarce and food is in short supply. We also need the freedom to stimulate our senses and exercise our muscles. In addition, we instinctively seek sufficient and secure shelter where we can grow, reproduce ourselves and bring up our young in safety. Our physical needs are intimately bound up with our emotional needs.

If these needs are not met as we grow up, we easily become needy, greedy, angry, anxious and depressed – forms of emotional arousal that, when we are in thrall to them, reduce our humanity and lead to all the miseries and cruelties in the world. When it is more widely recognised that one of the main responsibilities of every type of human group, from the family to the largest institution, is to help ensure that the physical and emotional needs of every child and adult with which it is engaged should be met, life will be more rewarding in every way.

## **Men Only.... Vol. 2 Nottingham 13-15 May 2005**

**Men Only....Vol 2, followed the success of Men Only, an event specifically for male registrants of the Trust which took place in Spring 2004.**

**Men Only...Vol2 was once again funded by the Macfarlane Trust, supported by The Haemophilia Society, and co-ordinated by registrant Richard Oakley.**

Men Only....Vol 2 took place at The Nottingham Royal Moat House and was attended by 23 registrants, four MFT staff including the CE and the CE of the Haemophilia Society who were also present.

Everyone who found the hotel, met on the Friday night in the hotel bar. where people got to know each other, put faces to names and old friends reunited.

The sessions kicked off on the Saturday morning when Jude Cohen presented the early findings from the recent mini survey carried out by the MFT. She explained how these findings, along with those from the Long Term Review. would be used to determine Trust services and be included in the impending funding bid to the Department of Health for increased financial support. A lively debate followed and a number of interesting points were raised.

Robert James reported on the success of The Haemophilia and HIV Life History Project, and also played some extracts from interviews This project, funded by The Heritage Lottery Fund, has collected life histories of people with haemophilia and HIV infection and is stored at the National Sound Archive in the British Library.

(See: <http://cadensa.bl.uk/uhtbin/cgiisirsi/Tue+Jun++7+13:46:02+BST+2005/0/49> and then search for "haemophilia and HIV").

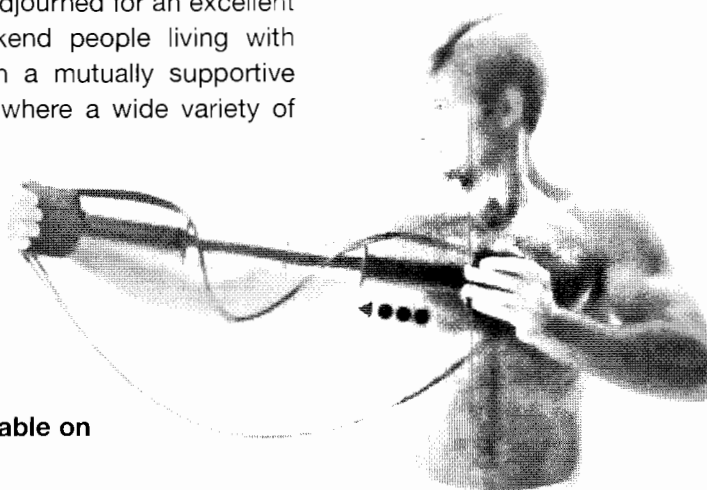
The afternoon session was called "Don't look back in anger" and was facilitated by Mike Beard ( The SPACE-HUMAN GIVENS consultancy) who took us on a fascinating journey of discovery encompassing sleep patterns, dreams, anger and the baked bean aisle of Sainsbury's. If this sounds confusing I'm not surprised but you had to be there to understand. Mike's session helped us all to look at our lives and how our situation has affected the way we live and concluded with Mike taking us through a relaxation process using breathing exercises that can be used in our everyday lives.

For further information about Human Givens please go to [www.humangivens.com](http://www.humangivens.com) or see the article by Gareth who was one of many inspired by this talk.

All delegates had been offered complementary therapies provided by, The Holistic Health Team, which had been arranged for individuals on an appointments basis throughout the day. On Saturday evening we met up in the hotel bar and then adjourned for an excellent curry just round the corner from the hotel. Over the weekend people living with haemophilia and HIV had the opportunity to get together in a mutually supportive environment that was both stimulating, safe and welcoming, where a wide variety of issues were discussed openly. One of the most important aspects of these events is to enable registrants to meet up in a relaxed setting to exchange views and experiences while at the same time to be stimulated and maybe learn new things about themselves in order, hopefully, to take on the challenges we all face in a positive and refreshed light. It certainly did that for most who attended.

**An evaluation and full report of the event by Richard is available on the MFT website. [www.macfarlane.org.uk](http://www.macfarlane.org.uk)**

*Birchgrove would like to express our appreciation to Richard for putting so much energy into organising a variety of successful weekend events such as Men Only- SFW- SFS, which are so valuable to registrants.*



# SOMETHING FOR SCOTLAND

Glasgow 9th-11th September 2005

Over the years the Macfarlane Trust, Haemophilia Society and Birchgrove have run residential events for people living with a bleeding disorder and HIV in England and Wales. Many people living in Scotland have asked for their own event so "Something for Scotland" was arranged as a joint event with the Eileen Trust (the Trust which supports people infected with HIV through other medical treatments).

The event was held at The Radisson SAS in Glasgow which is a modern hotel in the centre of town, and guests staying that weekend included 50 Cent and his homies who were in town for a gig.

People were given an opportunity to meet and get to know each other over the weekend in a supportive environment. Sessions were run for registrants of both Trusts and others separately. Everyone benefited from a range of complementary therapies provided by The Holistic Health Team.

MFT registrants had a chance to talk with Peter Stevens, Chair of MFT, and put questions to him about the role and future of the Trust. This session was lively and Peter talked about the Trust's current plans to approach Government for further, increased funding for the three years from April 2006. The Trust will be sending out information about the bid when finalised.

In the afternoon Sian Edwards made a presentation on "Living Stories" -The Haemophilia and Hiv life history project. Sian and her colleagues are hoping to gain funding for a future project to include partners and parents of those affected, for further information please contact Sian at S.L.Edwards@bton.ac.uk.

The final session on Saturday was facilitated by Brian West from HIV Scotland ([www.hivscotland.com](http://www.hivscotland.com)) who outlined current services and support organisations in Scotland. Interestingly plans are afoot to merge a number of HIV agencies in Scotland, a similar situation to that in England over the last few years and may involve what some refer to as the THT takeover.

Sunday started with a presentation facilitated by Roddy Morrison, Chair of The Haemophilia Society and joined by fellow Trustee of The Society, Phil Dolan. Their session concentrated on the support and information work the Society is currently involved in with particular reference to the local situation and campaign issues.

The final session of the weekend was a joint viewing of a BBC Scotland documentary called "Blood and Tears". This documentary looks at the situation surrounding contaminated blood and blood products in Scotland and is essential viewing for anyone affected by the issues living in the rest of the UK as well as Scotland.

The event was coordinated and organized by Richard Oakley with assistance from Roz Riley and Susan Daniels from the MFT. The event was funded by the Macfarlane Trust with support from the Haemophilia Society, Baxter bio-Science and Wyeth.

A full report is available on the MFT website [www.macfarlane.org.uk](http://www.macfarlane.org.uk) or contact Richard @ [Richard@macfarlane.org.uk](mailto:Richard@macfarlane.org.uk) or [richard@haemophilia.org.uk](mailto:richard@haemophilia.org.uk)

Everyone benefited from a range of complementary therapies provided by The Holistic Health Team.



# Snippets and Briefs

## MFT Summer Payment- welcome back

Birchgrove welcomes the return of the summer holiday grant which was removed from registrants options many years ago. The Summer Holiday grant enabled registrants to have a break in the summer without having to make individual requests to the MFT and prove a case for respite. Now it is back we can do the same and use it to our own discretion, and is available to all.

When the grant was removed, conditions were attached to requests that registrants must spend 3 days in hospital to qualify for respite. Over the years registrants and members of the Partnership group have argued for its return and equality for all.

Elizabeth Boyd's proposal and full support of the National Support Services Committee (NSSC) for the return of the summer payment does come with some conditions however. MFT guidelines now mean that all requests for respite breaks will have to be considered by the NSSC, supported by a specific recommendation from a medical practitioner that the respite will improve an individuals health. If you are refused a respite break or feel you need breaks more often there is no limit to the amount of times you can apply.

It may seem strange to outsiders that a panel of people who are there to support our health and wider needs actually need to sit and discuss the merits of a respite break, whilst qualified Doctors, who are busy enough already, have to spend their time writing a letter stating that " a break will improve my patients health".

## Blood victim awarded compensation

### 20/9/05 BBC News

A former MG Rover worker has been awarded £750,000 after contracting a virus similar to HIV during an operation at a private hospital where he was given a blood transfusion during surgery for pancreatitis at Nuffield Hospital, Birmingham, in 1995. One of the five blood units he received was infected with the T-Cell Lymphotropic Virus Type 1 (HTLV-1).

The National Blood Service (NBS) admitted providing defective blood.

The NBS had failed to screen it for HTLV-1.

Mr Best has since developed HTLV-associated myelopathy, a rare blood-transmitted disease which affects the central nervous system.

The High Court in Birmingham awarded the 64-year-old £750,000 following seven years of legal action. Mr best said "**I thought that after all the HIV incidents, that they screened blood for everything**"

Full story <http://news.bbc.co.uk/1/hi/england/hereford/worcs/4263714.stm>

Following this story breaking, Birchgrove reader Andy Evans did a ten-minute live radio interview with BBC Hereford and Worcester with one of their presenters, Howard Bentham. During the interview parallels were drawn between our cases and that of Mr Best.

Andy commented that "it's a pleasant surprise to actually be remembered and chased up by the media as opposed to having to fight for air time... maybe we're actually making a dent in the brick wall after all...?"

TLV-1 is endemic in Japan, the Caribbean, south-eastern United States and parts of South America and Africa.

It is estimated that 20 million people worldwide are infected with HTLV-1.

People infected with HTLV-1 or 2 have a low (5%) risk of developing disease and many people do not show symptoms until decades later.

By December 2003, 0.0002% of donations tested were found positive for HTLV, according to National Blood Service data published last year.

## **Birchgrove Woodland**

The Woodland Trust "Woodland Creation Scheme" Associate News- summer 2005 edition, has reported more Owls spotted at Stratton wood. Tawny Owls have been nesting and Barn owls have been spotted along with Sky Larks and Deer. With Cowslips in spring and a range of summer wild flowers such as Ox- eye daisy, yellow rattle and primrose mixing in with the meadow grasses, the area is starting to see a greater range of biodiversity as the woodland evolves.

The car park is having a temporary resurfacing at present with planned proper resurfacing next year. The first 50 meters of the path has also been resurfaced allowing access to the Birchgrove site a bit easier for the less able.

If you want more information about the Woodland Trust please contact 0800 026 9650 or [www.woodland-trust.org.uk](http://www.woodland-trust.org.uk)

## **Life Histories Project future plans- "HIV in the Family"**

The successful team that produced the haemophilia and HIV life history project have just applied for funding for a follow up project to be called 'HIV in the Family'. If Heritage Lottery agree to fund the project an archive will be created in the British Library Sound Archive to add to the Haemophilia and HIV Life History project.

What emerged from the last project was that behind the life histories of those who are alive there are more hidden, silent voices of those who have played a vital role through those challenging years. The partners, parents and children who witnessed their loved ones face the challenges of HIV infection, or were present as many of them died.

If you are a partner, parent or child of someone with haemophilia and HIV infection and would like to be involved in this project to preserve this important piece of history please contact the project team who will take your details and contact you later in the year.

The project team can be contacted by email [S.L.Edwards@brighton.ac.uk](mailto:S.L.Edwards@brighton.ac.uk)

(See: <http://cadensa.bl.uk/uhtbin/cgiisirsi/Tue+Jun++7+13:46:02+BST+2005/0/49> and then search for "haemophilia and HIV").

## **i-Base website redesigned- [www.i-Base.info](http://www.i-Base.info)**

The website for HIV I-Base has been totally redesigned so that it is faster and easier to use, and also more accessible for people with impaired sight. All I-base publications are available on the web site , including treatment guides and access to all archives and extensive range of links.

## **HIV/HCV Coinfection- Special report**

The first of a 2 part article on HIV and HCV coinfection by Dr L Davies MD MSc on behalf of HIV I- base was printed in August 2005 edition Vol 6 Number 8 HTB(HIV Treatment Bulletin). Part 2 of this article will be printed in a future edition. This can be viewed and downloaded form the web site [www.i-base.info](http://www.i-base.info)

Part one covers the epidemiology, natural history and diagnosis and clinical course of the infections with a host of references.

## **Thanks to Charisma**

Birchgrove would like to thank Charisma Design and Print Ltd for their service over the last four years. All the staff at Charisma who have been involved with the production of the last 16 issues of the Birchgrove Newsletter have always been friendly, helpful and importantly have shown interest and respect for our situation, and issues raised in Birchgrove. Many thanks.

[www.charismaprint.com](http://www.charismaprint.com)

# Snippets and Briefs

## **vCJD Test Moves A Step Closer**

Scientists at the University of Texas have reported that they are a step closer to developing a blood test to detect vCJD proteins (prions) in the blood, raising hopes that it may eventually be possible to screen humans. The team also hope that the technology could be effective in preventing the transmission of vCJD via donated blood.

The method is called protein misfolding cyclic amplification (PMCA), and has been trialed using hamsters. Prions were identified in the blood of 16 out of 18 infected hamsters, but none were detected in blood samples taken from a healthy control group.

Further research is required to determine whether the test could be transferred to humans, and if it would be effective, however the CJD Support Network has welcomed the development.

## **Internal Inquiry– Answers or another cover up?**

In 2002 the minister for public health (Hazel Blears MP) commissioned an internal review in response to comments, made by Dr David Owen (Lord) that the government were guilty of maladministration concerning his policy and drive to self-sufficiency during the period after he left his position as health minister in 1976. The review was asked to look at all government papers between the period 1974 to 1987 relating to the subject of hepatitis and self-sufficiency in blood products including the production of treatments needed for the haemophilia community in the UK from the voluntary donations provided by the British public.

The internal review after 3 years is now finished and should be available this Autumn. This review was internal and the content and results will not be known until it is published by the Department of Health. Whether this will give any new change of direction by the government, answers to our questions or just another cover up of the truth is to be seen. No doubt all our readers will be keen to see this and react accordingly. Look out for postings on MFT, Haemophilia Society and Birchgrove web sites.

## **US LITIGATION**

Judge Grady will issue his decision regarding the FNC probably late November or December we are informed. The result of the FNC decision is very important to UK clients and the case as a whole. This will decide whether the case will proceed in the USA. There will be grounds to appeal if permission is refused, and alternatives may have to be evaluated. For updates and comments for MFT registrants see the Bulletin board on [www.macfarlane.org.uk](http://www.macfarlane.org.uk) . For updates on progress see [www.lchb.com](http://www.lchb.com)

## **New Trustees**

Birchgrove would like to welcome 2 new trustees who have featured in the role of Birchgrove over the years.

Adrian Melson became Trustee of the MFT over the Summer, and Gareth Lewis became a Trustee of The Haemophilia Society as from the AGM on 17th September.

Birchgrove wish Adrian and Gareth the best of luck in their roles and hope their personal experience can help mould future services for the benefit of all of us, and both organizations.

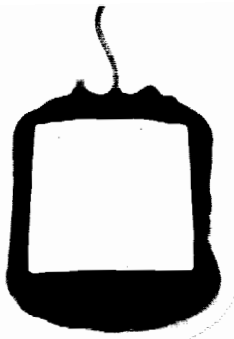
## **P-Selectin – A New Treatment?**

Scientists at Harvard University have reported that P-selectin, a protein found naturally in the blood, plays a significant role in blood clotting, and could become a treatment option for people with haemophilia.

The research asserts that patients would be unlikely to develop antibodies to the new treatment because P-selectin is carried naturally in the bloodstream. In addition, it has a longer half-life than clotting factor, so treatment could be less frequent.

The research was presented at the XXth Congress of the International Society on Thrombosis and Haemostasis on 10 August 2005.





# The Haemophilia Society

Due to health reasons, Graham Whitehead left his position as Chief Executive of the Haemophilia Society this summer. Birchgrove would like to thank Graham for his work at the Haemophilia Society and his support for Birchgrove. We also wish him good health on behalf of all of our readers.

The new Chief Executive of the HS is Margaret Unwin who has come from "Care for the Carers" an agency in Eastbourne. She also once worked for the Blood Transfusion Trust in New Zealand so lets hope she learnt lots about blood borne viruses while she was there.

The Haemophilia Society held their AGM on Saturday 17th September where

Retiring trustees were Ian Hayes, Alex Susman-Shaw and Rona Macdonald.

New trustees are Birchgrove veteran Gareth Lewis, together with Paul Bullen, and Debra Pollard. Richard Oakley was awarded a gong for Society Volunteer of the Year.

For anybody who wants to get involved with the Haemophilia Society their contact details are below. For people who do not have access to computers that want regular updates on Haemophilia news the Society produces HQ- The magazine of the Haemophilia Society. The Society web site has discussion forums, information on haemophilia centres, information and advice, publications and research and a telephone support network as well as a platform for its current campaign aims which we have detailed below.

## The Haemophilia Society and current Campaign Aims

**To call for an enquiry into the tragedy of contaminated blood products that infected people with haemophilia with HIV and hepatitis viruses**

The infection of the haemophilia community with HIV and HCV has been described as one of the greatest tragedies in the history of the NHS - and yet no official inquiry or report has ever been carried out. The Department of Health refuses to hold an inquiry, yet internationally Canada has conducted a wide investigation, Ireland has held full official inquiries and has provided compensation to those people infected. In France, Japan and Switzerland government ministers have all faced court cases over the infection of their haemophilia community.

## What is the Society doing?

Asking members to encourage their MPs to join the All Party Parliamentary Group on Haemophilia. The APPG on Haemophilia was re-launched at a reception in the House of Commons on Monday 11th July 2005. We are still asking members to encourage their MPs to join.

The Haemophilia Society web site has copy letters to download in word/PDF format for you to just add your own details, print off and post.

Corresponding with the Department of Health on the situation with regard to those who have been rejected from Stage One payments of the Skipton Fund and the proposed appeals process. Also, corresponding regarding the criteria for the Stage Two part of the fund. This correspondence is ongoing.

Researching a sample of members in respect of the adequacy of Skipton payments.

On Tuesday 12 July 2005 a meeting was held of the various organisations and individuals around the country who have been involved in the campaign for people infected with hepatitis C and HIV. The aim of the meeting was to create an agreed process for sharing information and to enable the various campaigners to stay in contact.

**The next meeting will be organised once the new Chief Executive, Margaret Unwin, is in post. Details will be announced to interested parties.**

### Contact:

**The Haemophilia Society  
First Floor  
Petersham House  
57a Hatton Garden  
LONDON EC1N 8JG**

**Tel: 020 7831 1020 Monday to Friday 9 am to 5 pm**

**Fax: 020 7405 4824**

**Freephone helpline: 0800 018 6068 (Monday to Friday 10 am to 4 pm)**

**Email: [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk)**

### Service of Thanksgiving– 29th October

The Rev. Preb. Alan Tanner will be holding his annual service of thanksgiving for people with haemophilia, who have died from HIV or HCV as a result of receiving contaminated blood products. This year's service will take place on Saturday 29th October at 3pm at St. Botolph without Bishopgate church (London, near Liverpool St station).

Anyone who is bereaved are reminded that they are welcome to have the name of their lost loved one placed in the book of remembrance held at the church. (See Haemophilia Society for further details)

### Mainliners International Conference– 16th-18th November

Mainliners are holding their 9th International Conference in conjunction with Deutsche AIDS-Hilfe e. V. in Berlin Germany between 16th and 18th November Tel 020-7378 5495 for information.

### HIV and hepatitis C co-infection update

Monday 24th October 2005, 7pm to 9pm  
Cockburn Lecture Theatre, 2nd floor,

Queen Elizabeth the Queen Mother Wing, St. Mary's Hospital, Paddington

This event is aimed at people living with both HIV and hepatitis C infection and will include time for questions and answers. Entry is free and light refreshments will be provided.

For further information, including how to get there, visit [www.ukcoalition.org/hepc](http://www.ukcoalition.org/hepc)

Supported by Roche and Imperial College London

### World Aids Day 1st December

World AIDS Day is now in its 18th year and this years theme is **Wise Up. Wear It. Where's Yours?** For more information about how to get involved in supporting WAD see [www.nat.org.uk](http://www.nat.org.uk) [www.worldAIDSday.org](http://www.worldAIDSday.org)

### Joke by Martin

Man with haemophilia goes to see a doctor:

Doc - "Hello, how can I help you?"

Man - "I've got an orange willy!"

Doc - "What?"

Man - "My willy - it's turned orange."

Doc - "Umm... I'll have to look that up. Ah, it seems it could be a sign of stress; do you suffer from stress?"

Man - "Not really, I've just had my summer payment from the MFT and had a holiday in Spain which was just what I needed"

Doc - "Hmm, what about your home life and relationship?"

Man - "Well, my girlfriend was a complete cow, she nagged non-stop and always wanted to spend my DLA on buying her new shoes"

Doc - "That sounds stressful"

Man - "Yeah, but I left her and I've never been happier."

Doc - "Are you having a lot of bleeds?"

Man - "No, since my elbow operation I can do anything with it and it never bleeds"

Doc - "I see, what about your social life?"

Man - "Social life? I don't really have one."

Doc - "Really? What do you do in your spare time?"

Man - "Watch porn and eat Wotsits."



# The Macfarlane Trust - an update

## The MFT admitted that they had failed the bereaved in the past

The MFT is undergoing constant change it seems, and many registrants involved in completion of the Long Term review last year expected to see changes and improvements to our service provision as a result of the review. However the reality at present is that registrants are seeing services dissolve and erode.

At a Partnership meeting on 23rd September registrants had an opportunity to discuss some of the more important issues.

Jude Cohen, Head of Support services, left the MFT on 1st September. As there were no support services in place for her to be head of this has left the Trust with no social services/welfare support available to registrants. Also the Trust has been without a Benefits adviser for some months and Martin Harvey stated that the post had been advertised and they would hopefully soon have someone in position.

At present everyday enquiries to the Trust are being handled by Roz, office manager and Martin, Chief Executive, until the situation can be resolved. Obviously Roz and Martin have no expertise in either social services, welfare rights or benefit advice. Martin suggested that the Trust were looking into working with social services support within our own comprehensive care centers. However registrants explained that services across the UK were far from perfect, some registrants do not access local hospitals and some comprehensive care centers have no social service support themselves, even though they are supposed in order to attain comprehensive care status.

Suggestions were given that the Trust in the meantime find specialized support for registrants either from existing social workers based in hospitals with relevant experience or via the THT. The group stressed that current service provision was inadequate and that the Trust were failing in its duty to support registrants.

To help our situation the Trust are expected

to distribute some new guidelines which should alleviate any concerns and misconceptions as to what we can apply for and how we can go about it. Martin said he wanted to reduce the bureaucracy and have clear transparent guidelines.

Plans have started to introduce a new "mini partnership group" with the aim of being able to meet with the Trust more regularly and with specific remits to challenge and improve the running of the Trust, advocating on registrants behalf. This is hoped to be more effective in implementing change than the current partnership agreement.

The MFT are in the process of completion of their 2006 funding bid, which should be handed to the Department of Health before Christmas. This has been based on our needs in line with the Long Term Review and questionnaires completed by registrants over 2005. Present funding for the MFT runs out in April 2006 and the content and success of this funding bid will be extremely relevant to all registrants.

The MFT admitted that they had failed the bereaved in the past and funding for this group will be specifically aimed at bereaved rather than just widows. A survey into needs of the bereaved has just had its results published and the Trust want to extend their bereavement project in 2006.

The Trust are also advertising for 2 new Trustees at present, with one post available for Chairman's position. Peter Stevens will be shadowing the successful applicant to facilitate the handover.

To end on a positive note, the Bulletin Board and Chat room on the MFT website are becoming increasingly popular with registrants visiting the site daily. The bulletin board itself has over 300 different threads of topics. If you are a registrant with no access to a computer Birchgrove suggest you approach the Trust for a single grant towards the cost. Best of luck.



# <new>www.birchgrovegroup.org</new>

It wa'n't like this when I were a lad.....ya knew where ya was with a bit o' paper in yer hand.

True enough, the 21st century has seen leaps forward in technology and the way information is presented to us, the people who read it. The internet has almost become the first stop for the current generation to find out anything they need to know, from the latest football scores to share prices to how much they can sell Granny's priceless Wedgewood for on eBay when she's not looking. If you're publishing information, you have the major advantage that your overwhelmingly interesting facts on the breeding habits of Caretta-caretta turtles over the past 400 years will be available to several billion people, instantaneously.

For many, however, the internet is a truly baffling place... a minefield of misleading, confusing, irrelevant information to be avoided at all costs, and that's if you've the confidence and basic training to be able to use the technology to get you there in the first place. It's still very true that for many, newspapers, newsletters or magazines are ideal for their information gathering needs.

So it was with mixed feelings that I received notice that Birchgrove was to make the move from paper to PC. See, I quite like to have the feel of that magazine in my hand as I'm chortling uncontrollably at the antics of Bob the Bleeder, and the feel of those or so pages beneath my fingers reassures me while I learn about the next new thing that's going to attempt (and fail) to kill me. But I know as a web designer the power of the internet when it's used correctly, and the immediate benefits in terms of cost, outreach and immediacy of pushing out your info onto the web.

To put it simply, as a long-time Birchgrove reader I know how important Birchgrove has been to so many over the years, and am honoured to have been asked to create a new Birchgrove website to replace (and hopefully expand upon) the newsletter.

The new site is an information portal into Birchgrove, from its long history to current projects such as the Woodland Grove in Stratton Wood, its links with other organisations, and an archive of its newsletters, readable online, for the whole world to see. More than that, it includes tools for the Birchgrove team to use to insert news items, so that the latest news and information will always and immediately be available to us, its reader base, and also to anyone else interested in looking at the site.

As soon as you type in [www.birchgrovegroup.org](http://www.birchgrovegroup.org) into your browser and click Go, you're presented with an introduction to the new look site and links to its various areas. The navigation ring will always be available on this page (and the nav-bar at the top of every page) for you to jump to the following areas of the site:

- History: a history of the Birchgrove group
- News: the main area in which the latest news stories will be presented, viewable by a date-ordered list, with the latest story appearing first
- Contact us: a page via which the Birchgrove team can be contacted
- Woodland project: information on the Woodland Grove in Stratton Wood
- Links: a list of links related to the work of Birchgrove and those its reader may find interesting or useful
- Newsletters: an archive (in PDF format) of the entire back-catalogue of Birchgrove newsletters

Simple as that. After all, we've all got enough complication in our lives, right? Is it more complicated to use than turning the pages of a magazine? Possibly, but I hope not by much... and I hope you'll agree with me on that.

So, it's the end of one era and the beginning of the next. I hope that it's a positive change... I think it is... at the very least it will be a lasting legacy to the amazing history of Birchgrove, hopefully will facilitate the ongoing existence of Birchgrove for many years to come, and I am proud to have been a part of that.

Any comments welcome either to the Birchgrove team via the site, or to myself at [andy@design-graphix.net](mailto:andy@design-graphix.net)

**Andy Evans**

**Webmaster**

### **Haemophilia Society**

Information, advice and support.

Tel: 0800 018 6068

Email: [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk)

**Website:** [www.haemophilia.org.uk](http://www.haemophilia.org.uk)

### **The Macfarlane Trust.**

Financial support for PWH HIV/HCV

Web based chat room for registrants.

Tel 020 72330057

**Web site:** [www.macfarlane.org](http://www.macfarlane.org)

### **National AIDS Manual**

Provides up to date factual treatment

Information, free publications+website.

Tel: 020 7627 3200

Email: [info@nam.org.uk](mailto:info@nam.org.uk)

**Web site:** [www.aidsmap.com](http://www.aidsmap.com)

Website for latest news and conference reports, searchable treatment database.

### **HIV and Hepatitis.com**

Online publication about treatment.

**Web site:** [www.hivandhepatitis.com](http://www.hivandhepatitis.com)

### **The UK Hepatitis C Resource Centre**

Information and advice for HCV+ people, professionals and the general public.

Tel: 0141 353 6969

Email: [advice&info@hep-ccentre.com](mailto:advice&info@hep-ccentre.com)

**Web site:** [www.hep-ccentre.com](http://www.hep-ccentre.com)

### **British Liver Trust**

Information, advice, support and campaigning on all aspects of liver disease, viral hepatitis, publications and web based details.

British Liver Trust, Portman House, 44 High Street, Ringwood, Hampshire,

BH24 1AG.

Tel: 01425 463080 Fax: 01425 470706.

Email: [info@britishlivertrust.org.uk](mailto:info@britishlivertrust.org.uk)

**Website:** [www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk)

### **Mainliners**

Support, advice and information for people affected by drugs, HIV and hepatitis.

Tel: 020 7582 5434

Email: [linersmain@aol.com](mailto:linersmain@aol.com)

**Website:** <http://members.aol.com/linersmain>

### **Positively Women**

Peer-support services to HIV positive women and their children. Drugs and alcohol support group and bi-monthly newsletter.

Tel: 020 7713 0222

Email: [info@positivelywomen.org.uk](mailto:info@positivelywomen.org.uk)

**www.positivelywomen.org.uk**

### **Positive Nation**

Monthly publication providing a platform for all people affected by HIV and AIDS in the UK.

Tel: 020 7564 2121

Email: [subscriptions@positivenation.co.uk](mailto:subscriptions@positivenation.co.uk)

**Website:** [www.positivenation.co.uk](http://www.positivenation.co.uk)

### **+ve**

Monthly publication about HIV and quarterly issues about hepatitis

Tel: 01895 637878

Email: [andrewb@akitonet.co.uk](mailto:andrewb@akitonet.co.uk)

**Website:** [www.howsthat.co.uk](http://www.howsthat.co.uk)

## **National Helpline Numbers**

### **HIV i-Base**

HIV treatment information and support.

Tel:0808 8006013 Mon-Wed 12-4pm

[admin@i-Base.org.uk](mailto:admin@i-Base.org.uk)

**www.i-Base.org.uk**

### **National AIDS Helpline**

0800 567 123

24 hour helpline offering advice on HIV/AIDS

### **Terrence Higgins Trust**

0845 1221 200

Mon-Fri 10am-10pm Sat- Sun 12-6pm

### **AIDS Treatment Phone line**

0845 947 0047

Mon + Wed 3pm-9pm Tues 3pm-6pm

### **Positive Line**

0800 1696806

Mon-Fri 11am-10pm Sat/Sun 4-10pm

### **Immune Development Trust**

Offers broad range of holistic therapies and advice to HIV+people

Tel 020 7704 1555

**www.idt.org.uk**

### **Haemophilia Wales**

1st Floor 100 Whitchurch Road.

Whitchurch.

Cardiff.

CF14 3LY

telephone 029-20372719

### **Birchgrove North**

c/o Body Positive North West.

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## DISCLAIMER

The views expressed in each of the articles are those of the individual authors, and not necessarily those of Birchgrove.

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## Birchgrove is a Forum for:

**The treatment of haemophilia  
and HIV**

**Taking best care of ourselves,  
through informed debate.**

**Staying healthy with both  
haemophilia and HIV/AIDS**

**Ways in which HIV affects love  
and sexuality**

**The social and psychological  
aspects of haemophilia and HIV.**

**We believe that people  
with Haemophilia and  
HIV...**

**Can be empowered and  
enabled to deal with HIV/AIDS  
through relevant information  
and mutual support.**

**Can improve their health and  
extend their lives by expressing  
feeling and confronting the  
issues directly**

**Should be heard and have their  
needs recognised and not  
suffer in fear and isolation.**

**Have a role in the work of the  
HIV/AIDS community to inform  
and challenge the ignorance  
that exists about HIV.**

## AND NOW THE END IS NEAR...

Birchgrove Newsletter is disappearing into cyberspace. This will be the last one to drop through your letter box. "Thank heaven, no more Bob the Bleeder" I hear you all cry. The newsletter started aeons ago and has been through a number of different styles, editors, writers and printers. We asked if anyone would continue it but aside from a request for an Annual General Meeting from one of the Haemophilia Society Trustees (was the one at Stansted Airport not enough for this year??) and quite a few emails expressing disappointment it was to stop, no offers to take over.

We've had highs and lows along the way. One editor who shall remain nameless put in an article that questioned whether HIV was the cause of AIDS, just as a medical paper came out showing that haemophiliacs proved HIV was the cause of AIDS!! He gave up and started writing science fiction rather successfully so perhaps we should just see the article as one of his first attempts. Gareth's front page article from 1999 "Last Will and Testament - Never to be a Trustee" and yes, that would be the Gareth you read

about earlier becoming a trustee of the Haemophilia Society. We enjoyed the sex and drugs issues so much that when the current lot started producing the newsletter we repeated the topics again.

Hepatitis C remained with us throughout and appeared in the magazine again and again. Likewise court cases about infection, ours and other people's have lasted as long as the newsletter. A special issue on HIV in Africa accompanied the Christmas 2000 issue to show that we could look beyond our own problems as well. The headline I liked best of all was from newsletter 3 was "From victims to survivors" and if you are reading this you all saw the millennium, England win the Ashes and outlived the newsletter which I bet none of you thought you would in 1990!

Sadly far too many did not survive, Pete whose obituary appears earlier and many others important for Birchgrove and the newsletter, particularly Meirion, Jenks, PK, Cady and Deborah. And for those of you reading this - we'll see you in cyberspace.

[www.birchgrovegroup.org](http://www.birchgrovegroup.org)



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AWARDS FOR ALL