

## Living Stories

In 2003 the Haemophilia and HIV Life History Project that was based at Brighton University and funded by the Heritage Lottery Fund began. The project aimed to record interviews with 30 haemophiliacs with HIV about their lives and experiences. The recordings have been placed in the British Library. All the interviews have been archived, and copies of each recording and transcripts of the interview sent to everyone who took part. This means a rich historical resource about the experiences of haemophiliacs with HIV will be preserved in the British Library Sound Archive for the future. The personal perspective of this dramatic medical and social event where 1,200 people in the UK were infected with HIV through the use of contaminated Factor Eight treatment has been captured for later generations to hear how it felt from the people who lived it.

Doctors, social scientists and journalists have written extensively about the social, medical, legal, political and psychological issues that surround those with haemophilia who were infected with HIV in the early 1980's but the voices of people with Haemophilia and HIV, those most intimately involved, have rarely been used. The personal experiences of the people recorded for this project are invaluable in ensuring a more complete historical picture of this major social, political and medical event is available in the future.

The interviews highlight the great difficulty of coping not only with the likelihood of an imminent death but then adjusting to the possibility, but never the certainty, of a future. These deeply personal memories

and experiences will now be preserved; they provide an insight into how people re-adjust to a life that they did not expect to have. Despite the trauma in remembering past events and the painful awareness that those past events are still shaping their current lives; those interviewed express immense gratitude and pride that their stories will become part of the recorded history of HIV in the UK. This issue of Birchgrove gives itself over to the voices of the people that took part; the people recorded, the people interviewing them and the people that made it happen.

The aim of this project is to enhance peoples understanding and appreciation of Haemophilia and HIV in Britain. The themes and issues that emerge from these life stories are being analysed and developed into a source of information to be presented at conferences, utilised in teaching packs for health care staff and presented to a wider public audience through radio broadcast and a website. Ultimately the researchers intend to collate the stories into a book.

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Life History Project Participants and supporters at the Woodland Grove on a cold wet day in January

## The Research Team

**Siân Edwards** is a Senior Lecturer in HIV at Brighton University and previously worked as a Haemophilia Clinical Nurse Specialist.

**Robert James** is a Patient Consultant for the NHS Modernisation Agency and Chair of Birchgrove.

**Wendy Rickard** is an Oral Historian for the British Library and the Senior Lecturer in Public Health and Health Promotion at South Bank University.

**Krista Woodley** is an Oral Historian for Southampton City Council and is currently working on the Vosper Thornycroft Shipyard Oral History Project

The project also had an advisory group to help with technological, methodological and any other issues. It consisted of **Dr Rob Perks**, curator of the National Sound Archive at the British Library, **Dr Alistair Thompson**, Lecturer in Oral History at Sussex University and Joint Director of the Centre for Life History Research at Sussex University; **Chris Harrington**, Nurse Manager of the Haemophilia Centre Royal Free Hospital London **Stuart**, a haemophiliac with HIV and **Babs Evans** who was Co-infection Worker at The Haemophilia Society when the group was formed and now works for the **National Aids Trust**.

## Why we did it and how it felt

The research team produced a CD called "Living Stories" for the participants with an extract from everyone describing their motivation for being involved in the life history project. This is what they said.



**Mike:** I mean I'd heard talk about it before from a couple of people and it sounded to me like an exciting project, it sounded as though it was something that was very valuable and I from people that I'd known - through my involvement with Birchgrove, I knew that there were a lot of people with stories and some of those people we know are no longer around to tell them. I thought, well I've got a story to tell myself about my own life and no probably no-one's going to be able to tell it as well I did, as well as I can. And I thought well it would valuable perhaps to have that on record somewhere. I mean I'm terrible, I'm a very disorganised person and I leave notes and I sometimes keep diaries and then let them lapse and then take them up again and there's no cohesion at all to them. But I thought maybe this would be a good, a valuable tool. Not only for the project I mean I don't whether it'll be valuable for project but it'll

certainly be valuable for me if I ever do get round to reading it or if my wife gets round to reading it. So that was the main motivation for me to do it, to become involved with it.

**Ben:** It's important for us to get all our views down you know, the people that got infected, the Haemophiliacs. We've never really had this chance before, when I was told about it I thought it was a brilliant idea so, I wanted to be involved. It's been good to do this, I feel better now I don't feel depressed. I feel like I'm in more control of myself.

**Paul:** It's an opportunity to tell my story, and it's an opportunity to tell my truth as I see it. I think already what's happened to us as a patient group, the history has already been changed and altered to suit, I feel to suit people's beliefs and I'd like to give the story of what actually happened, what it felt like to have lived this. This is me who's still alive nearly twenty years after being infected. And I'm still very happy to be here but it's been a strange journey, and I think I'd like to have just give an opportunity to let people know. To let my nephews and nieces know in the future, people I can't tell now and for my story to be heard.

**Mark:** Basically I've been thinking of some, for some time of doing this sort of story. I think that a lot of things have happened to me in the last forty years and I think there's definitely a story there for people maybe interested. Maybe for other new mums and dads if they've got kids with Haemophilia, to actually hear what it was like probably from the 60s, all the way through to now.

**Suresh:** But I just feel that a great number

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*Cos, we're all gonna die, our children are gonna die and the memories will fade.*

of people are suffering in silence today and if there's nobody that can put a voice to that suffering then it'll go unheard and that's unfair, that. Just because somebody hasn't got a voice doesn't mean that they shouldn't be heard. If my interview can help shed some light on that, maybe not tomorrow but in years to come, then I'm all for it, really.

**Haydn:** I've feared for many years that what gets read in future generations about history won't be factual, it'll be what the government want it to believe or want the general public to believe. And that's a sin in my eyes because history is the only way that we'll proceed in life. If we don't learn from history then there's no hope for us.

**Gareth:** Cos, we're all gonna die, our children are gonna die and the memories will fade. History is written by government and this will tell our story.

**Richard:** I think that the history of people with haemophilia and HIV is being re-written by the Government. That makes me very angry and I would like, in the future, for people to actually understand what happened to us and what is still happening to us and what's happened to the people who've died. From my perspective, and not the Government or my doctor's or anyone else's. I think that people change history. Because history is what happens to people and if the truth isn't heard, then other people will tell the history for them. And I think, and a lot of my friends with haemophilia and HIV think that the government and some health professionals have rather hijacked it.

**Patrick:** It's nice to have our side of things down and we've in a way made a bit of a mark. Cos it's been such a pushed under the carpet thing, it's nice to still have our say and, let people of the future and the present just get an idea of what it's like living with all these different problems....I'd like to listen to what other people have got to say. How their life's been and I'm assuming that other people would like to hear how my life's been.

**Mick:** For me it's just the fact that there's gonna be a lasting memory of a good portion of haemophiliacs who have gone through the same as me. Yeah we've had little media stories here and there, but nobody really knows the whole truth of what's happened, nobody really knows the whole story and nobody really knows how we all have gone through it and what's happened to us. It's been said, on days in parliament, it was the biggest NHS disaster

in NHS history but nobody seems to want to acknowledge that, nobody seems to want to do anything about that and I think this is probably the only thing that will still be there when we've all gone. That and the Birchgrove stone hopefully!

**Robert:** It's been very interesting particularly if I am then going to be asking people to record theirs. So I think it has been quite important that I have an understanding of how it's felt. And I've thought quite a bit about what restrictions do I want to place on this? And I'm really not sure. I kind of want, I suppose I mentioned it earlier, the restriction that anyone can hear it except those people who I've insulted and those people who I might want to try and sleep with who I don't want to read it first or hear it first. It's felt good, I've enjoyed it and I'm sure like lots of people I've always thought I should try and write up or record my life in some way. I mean, initially 'cause I thought I was gonna die and friends of mine might want to read it in ten years, again being perhaps a touch egotistical or maybe my brother's daughter's children, or someone.

**Perry:** I've spoken about episodes of my life in my church and to other people as

I've known, as I've needed to, and just to try and give them some context

of who I am, and what I've been through. But this is the first time that

I will have gone from year zero to year forty-two.

**Tom:** It was easier than I had expected. I suppose I'm not...I don't recite what's happened to me to many people. I've certainly told stories to my mum and dad; I've told probably more detailed stuff to my sister and my other half; but then, they all know what's wrong with me. With my friends, they appreciate that I can't see, but they don't quite know...well they, they don't know exactly why I'm in this situation. So it makes it very difficult

**Stuart:** Primarily it's, as far as I'm aware, the first project looking specifically at the impact of HIV upon the community of haemophiliacs in the UK, so that's important to start with. Secondly it gives our community some identity and even though 850 guys have died, those who are remaining can have some sort of permanent voice about what happened to us, about the way we were treated, the personal experiences we've all had. I know some of the guys would have been talking about things that happened to us as a community, the problems of the 1980s, the way things



should've been done, the way we were told things, the way things could've been, might not have happened if things had been done differently by governments and stuff. And thirdly it's a record of my life personally and what's happened to me as an individual and how HIV has moulded me, my ideologies, my philosophies on life and the way that's developed me as an individual. And for me that's important because it's the whole crux of my life has evolved around HIV, I've never known any life other than having HIV and so being able to expand upon that in this project is really important and to have other people have access to my thoughts, whether it be family or friends or researchers or whatever, I think it's important and I think it's vital that these sort of things are archived for the future so that people understand what happened to our community in the 1980s.

**Ian:** It's been harder describing my life to that tape machine, than it has been on very many occasions recently describing my life to two and three hundred people in a room at a time. I guess I've realised that some of the public stories are not the ones that I've told the tape machine – not necessarily because I've been lying to other people but because you tell your story in different ways sometimes.

**Charles:** I mean first it was HIV, then it was Hep C, and it just seemed like one thing after another. And that's one of the reasons I wanted to do this. Things just seem to have happened without you having too much control, you're just put in one situation after another.

**John:** But you paint your smile on your face and you go out from your front door, paint the smile on your face and 'Hello yes, fine thank you.' And then when you close the door you scream, scream into your pillow or cry and then you do it again the next day. Sometimes it breaks through, screaming at the top of my head, shouting, screaming for help cos you hold it in for so long, like a coiled spring and bang!

**Catherine:** I have something that has an impact on my life, for my whole life that I have to learn to live with. And learning to live with something that will always have an impact is the hardest thing, and is something you need to keep revisiting again and again and again. So I tried to make everybody laugh. I'm still doing it, I'm doing it now, I can talk about it if I can laugh about, then at least I can accept it. If I really, really feel it, cos I can, it makes me cry – makes me sad. But I try to relate to myself as something that I've survived. It's been

really hard work, really hard work.

**Stuart:** The middle brother, John, he was a haemophiliac, caught HIV and he died in November 1991. He was in hospital for five weeks, he got progressively worse until he died. It was a peaceful death. And that was, well we were told, it was HIV related. And he didn't have time to spend to what, his thirty pieces of silver, if you want to call it that, well it was, it's just thirty pieces of brass, wasn't it? But no, he didn't have a chance to enjoy his bit of compensation – shame really. I sometimes wonder – why, why he died and not me? Because he'd achieved so much, John. At his funeral there seemed to be hundreds of people there. Friends and colleagues from work and since then I've thought off and on I've thought well, he achieved far more than me in his life and yet, you know, he was taken so early, he was 42, and yet I'm still here. It's funny how life goes, isn't it?

**Dave:** But I was in the two camps you see, cause I'm a gay haemophiliac. So I couldn't, my head was battered at certain things, cause everything, when we went to like at weekends or anything, it was all heterosexuals, there was nothing gay. So I thought, I'm not only haemophiliac, HIV positive haemophiliac, but a gay haemophiliac as well. I'm the only one. Which is quite bizarre when you're growing up and you come to terms with being positive, and then trying to come out as well – oh it's quite difficult.

**Mark:** People were being fired, people were being socially excluded, people were losing their families because they were HIV positive and this wasn't happening to me. I was in a church which not only accepted me but was linked to a charity which still exists operating in the Earls Court area which at that time, late '80s and early '90s was working with very disadvantaged, excluded people; rent boys, prostitutes, street people and AIDS patients who were dying. And this was the time when the church nationally was still throwing up its hands in horror and still having panic attacks over whether to share communion cups and this was the only one that I knew about that was getting stuck in there and involved and caring for people. People say encouraging things to me about perseverance and endurance and not letting it get me down and carrying on with life and always being cheerful and stuff – so that's certainly the outward face. It's a bit bleaker on the inside.

**John:** I've held so much in for so many years and able to express those I've held all

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that in for the last, what eighteen years, has broken some kind of film I suppose, like cling film and you've broke it and all what you've been bottling up and been angry with, you've been able to express some of that. And the anger I suppose and the not able to say anything in case you say the wrong thing.

**Derek:** Just to say that I hope this hasn't come over as too much doom and gloom.

My life is great. I've had an opportunity to meet and spend time with lots of interesting and amazing people and enjoy life. Easier than I thought it would be to be honest. It was easier than I thought it would be.

**Joseph:** And from this I would hope that someone will listen, and think, and take it on board, and will design a system where, when tragic events like this unfold in the future, if they ever unfold in this way again, that there will be a form of support made available that will be there immediately, that won't rely on a legal structure, to have to be proven that there's negligence.

**Andy:** Thanks coming up and doing that and hope it's not been too boring for you. My memory is not the best. Auch I dunno just sort of tried to give as honest an account o' things as I can. It's not all good and it's not all bad and there's a lot o' contrasting emotions and things the negatives, the sadness and the anger and everything. But then the positive side of living and surviving and doing things trying to help people and trying to help myself. Its all been a bit of a crazy journey. At least somewhere they'll be a record of what's happened and people's lives, even if we never get a public inquiry people will know that it was a cover up and thousands of haemophiliacs were, effectively, murdered in this country.

**Martin:** Mentally, I feel very old. I've always been told that I've got maturity well beyond my years and I do feel like I've been around a long time, I feel like a dinosaur at times and when I recall a lot of these events that have happened in my life, I can remember them so well and people say to me, you've got a fantastic memory for dates and years and things and in some ways I wish I had a poor memory. But at the same time, it makes me realise that I have had a very, very full and active life. I've done a lot. Some scary things, some not so scary but I've done things. Some people can sit down and think about their life and think, I haven't done anything. And I know I have, so I'm satisfied in that. I have a lot to be thankful about, I really do, but as I said, I've done a

lot in my life and it ain't over yet.

**Michael:** I feel good now. I think I've done something, you know, for people to, you know, to listen to, of what happened years ago, up to today you know? I'm just happy I done it.

**David:** Well, I'm seventy now. When I was born, the average age of a haemophiliac was eighteen years. My parents would be astounded to see me still alive. In fact last night I saw a philosopher talking on television, this atheism series, I'm a great atheist myself, and, he said that, you know, people ask, what is the meaning of life? Well the meaning of life is to live it. What's going on now. If you can live your own life, and live it to the full, then, that is the meaning of your life.

**Paul:** But I've really, really enjoyed it. It's been really positive experience. This isn't going to be just something that's going to be on the radio, or on tomorrow's television programme, or an article in the next month's whatever newsletter. This is going to be something that's going to be kept, forever. I think that's pretty important. I'm just a little cog in a wheel of all that's happening, all those other guys that have been involved in this, all the people that have made this happen. All the people out there not involved in this that have fought for haemophilia rights, for treatment, for recognition for all those people that have written letters to MPs and made a noise about our situation - it's for all of them, it's to make sure that we're not forgotten, even if I die of natural causes in a rocking chair at the age of 95 this has still been a traumatic experience for my life and has changed my life completely and changed my life in a way that I never expected, never anticipated.

**Andrew:** A lot of people use the word empowered. I see it as more having developed coping strategies, I suppose. And because I've talked about myself in a public speaking context in the past, I've possibly maybe even desensitised myself to some of the issues that might be difficult for other people to talk about. And if my situation is any way similar to theirs, I would like to think that this interview has kind of encompassed their lives as well as mine, so I'm not really trying to do it for me as such, although I think it is a great thing to have and to know that you'll be remembered and to know that there's gonna be a bit of history of you there that's not gonna be lost. I hope that this has helped not just myself but other people as well in our situation.

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# What it was like from the other side

I got involved with the Haemophilia and HIV Life History Project because of my interest in oral history and how it could be used around the history of healthcare and medicine. As far as I knew I had never met anyone with haemophilia and HIV before and my knowledge of the issues around haemophilia and HIV were pretty limited. When I first heard about the project I thought it sounded interesting and important - something I definitely wanted to be part of. Put simply, the project's main aims were to record the experiences and testimonies of thirty people who have haemophilia and HIV and to deposit those recordings in the British Library.

I was to interview people on a very sensitive subject about which I had limited knowledge. So plenty of opportunities to put my foot in it. And these conversations were not only to be recorded but also to be stored for posterity in a prestigious public archive. Daunting for the interviewees and daunting for me. The only option was to jump right in. And I have to say that each person I interviewed just gave me more and more enthusiasm for the project. People were hugely generous with their time, their stories, their photographs. They collected me from train stations when I went to see them, they fed me, gave me endless cups of tea, hugged me in some cases and were altogether charming and kind. And most importantly, they were interesting. Before doing an interview one of my biggest concerns is usually that I might end up interviewing someone tedious, opinionless, monosyllabic. No worries there - the people I interviewed were intriguing, opinionated and generally could talk the hind leg off a donkey.

Doing the interviews also made me even more passionate about the purpose of the project. I became more and more aware that many people participating in the project felt very strongly that the official story of what had happened had failed to reflect their own personal stories and experiences. This project was an important chance for people to set the record straight and tell their own stories in their own way.

Working on the project has been really interesting for me as an 'outsider' to get involved with a group of people with such a strong sense of community (both the Birchgrove scene and non-scene). But more than that, it's also just been a genuine pleasure to meet the people that I interviewed, and to meet all of the other project participants that I have met since.

**Krista Woodley**

*(Krista has now moved on to a prestigious Oral History project with Southampton City Council collecting oral histories of people who worked in the dockyards there. In her spare time she is still helping us collate, think about and organise the stories from the life history project into presentations and events)*

## Why I got involved in the Haemophilia and HIV Life History Project

I was really pleased when Robert and Sian asked me to be on the project steering group. In my role as HIV/HCV worker at the Haemophilia Society I had the privilege of talking to many people living with haemophilia or von Willebrand's and HIV. This was on the helpline, or by email, or face to face at an event and occasionally in the pub after a few beers. Every single person had something interesting and different to say about their experiences and yet people with haemophilia and HIV are often referred to as a 'community' with common needs and views. The commonality is having a bleeding disorder and the same virus or two, but that's where similarities end and individualities begin.

Right from the start I felt that the project was a fantastic opportunity to highlight the diverse and extraordinary stories, each one as unique as the individual. I also feel that there are many lessons other people living with HIV, health professionals, family members and friends can learn if they take the time to listen. This is why I was so keen to be part of the project.

So what have I contributed? Before the recordings started I put together resource packs for each of the interviewers. This was in case any particular issues of concern came up, the idea being that the interviewer could then pass on a leaflet, newsletter, helpline number or other information. As the interviews were being recorded and transcribed I attended the steering group meetings and contributed my ideas but didn't have much more to do until we started talking about the feedback day. This was the opportunity for me to use my conference organising skills. I suggested we held the event in Swindon so that we could include a trip to the Birchgrove Woodland Grove and began the work of finding a venue and putting together a budget. The National AIDS Trust, where I now work, kindly allowed me to use the phone, fax and email in order to liaise with hotels, crèche providers, coach companies etc and I wrote documents in my lunch break and after work.

The day itself, which we called 'Living Stories', went smoothly and the hotel staff were excellent and very efficient. We had one room to use for presentations and another where we played recordings of some of the interviews and displayed quotes and pictures. Over the years I had been in contact with the majority of people that took part in the project but I found that I still learnt some new stuff. The only thing we didn't have any control over on the day was the weather and unfortunately it rained just as the coaches were setting off to go to the woodland. Still this didn't seem to dampen some people's enthusiasm and highlighted the fact that the trees are a living and lasting natural tribute to the lives of people infected with HIV from contaminated blood. The Haemophilia and HIV Life History Project has enabled the voices of some of these people to be heard too.

**Babs Evans**



## The Feedback Day



### Diagnosis

In January this year the project hosted a feedback day for the people who had taken part and their families. It was an opportunity to let them know a bit about the similarities and differences in what everyone had talked about and a chance for them to say how it had felt. Siân, Robert and Krista spoke about what people had said about their diagnosis, the changing perception on mortality and disclosure quoting some of the positive, painful and funny things people said about each. It was also a chance for the people who had been interviewed to advise the research team on what could have been improved for a future project and to discuss the idea of how best to disseminate the findings.

**There was a very general feeling that a alongside presentations at conferences, a website and a book containing extracts from the stories would be the good things to promote understanding of the situation for people with haemophilia and HIV.**

Today people assume that you would find out an HIV diagnosis after having a discussion, giving consent to be tested and then receiving the information face to face with counselling, information and follow up support.

For some people there was a moment when they remember a face to face discussion with a doctor who informed them, of their diagnosis, and those experiences and how they were told are very revealing – about the medical professions' ability to impart bad news. The contrast with today was the enormous amount of stories where people discovered their diagnosis in a more vague manner and weren't told face to face. It will be interesting to analyse this deeper to see how it might have impacted on peoples' subsequent coping strategies.

Stuart talked of how the information seeps into his unconscious never remembering a day when he was given the information.

Mick was sent a diet sheet for people with HIV and AIDS – that was the first indication that he had.

Michael tells of how he was admitted to hospital for a knee operation and asks why it is that he is sitting a single room with danger of infection stickers on the door- that's how he found out.

Ben was informed, against the expressed wishes of his parents, by the playleader in the children's ward.

Dave tells a story of how his mother had received a photocopied letter telling her that her 10 and 12 year old sons had antibodies to HTLVIII, that she didn't understand the letter, didn't appreciate what it was saying and so never had a conversation with a health professional about the fact that they were informing her that these two small boys had two years to live.

There are many more examples but these were the quotes from Mick, Ben and Dave.

**Mick** *"but it wasn't till 85 and receiving a diet sheet through the post from the hospital. Yeah it was literally one piece of paper and it had all the, I can't remember the exact wording, but the top of it on one side it says "If you are having symptoms of HIV you need to eat this sort of stuff". And on the other side it says "If you are having symptoms of AIDS you need to eat this sort of stuff". And I remember being shocked at getting it and thinking, why the bloody hell have they sent me this? Silly arses, they've cocked up again. Threw it away. Got on the phone straight away. My mum was there as well. Phoned the hospital up and said "you've sent me a diet sheet for AIDS and I just want to know why." And they said they can't possibly talk about it over the phone, I need to make an appointment and come in. I said "I want to know now if I've got AIDS or not". "Can't talk about it over the phone, you need to make an appointment, come and see the doctor".*

**Ben - aged 12 when he was informed** *And I knew by what I'd watched on the news a good like five or six years before that, I knew there might be more, there might be more things that I was going to have to deal with you know. And she told me.. She said, well actually I don't I don't totally remember how she told me but she told me I was HIV positive right. And I, I said, 'yeah I know.' And she said, 'how do you know?' and I said, 'well you know I've heard about, I know about AIDS, I know and I know that haemophiliacs had something to do with it, or we were affected in some way.. So I wasn't shocked at all you know but I suppose that's a good thing I mean I must have been in shock a little bit but, it didn't seem it didn't seem a big, big thing then. I knew it wasn't good obviously and she said, 'okay,' you know 'let's let's go back.'*

**Dave** *Recently Mum showed me a letter that she'd received from the local hospital. And it was just like a photocopied letter with gaps and just my name and my brother's name put into the little gaps. Just like a letter you get from the Social or British Telecom or something like that. Just a bog standard letter and just our names put into it, not even signed or nothing. Just saying that, 'Dear Madam, your son's or somebody being tested positive for it blah-de-blah H,' whatever it was called then at the time. And my name and Robert's name just put in, in Biro and all the stuff about what it is. And then on a separate piece of paper it was stuff that she'd have to be careful what she did like it was the early days then, like with the toothbrushes, with the cutlery, with the plates, with the cups. And she showed me that actually, and when I was reading it I was like oh my God I couldn't imagine it. It just came through the post, it just came through the post, I just couldn't believe it. But I didn't find out until I was about 15 when I was in hospital.*



# CHANGING PERCEPTION OF MORTALITY

*How long I have left to live and what am I going to do before I die are not questions most people face when they are young but this is exactly what everyone had to do. Not surprisingly this had a huge impact on people and the ways they lived their lives.*

## Thinking back before HIV:

**Joseph** *haemophilia, for all its severity, was never a challenge that I imagined I would lose to. I always believed that I could fight back from any bleed, and I could always make life work in my favour; there was always a, a real self-belief, a determination, and, a positiveness*

## And then it came

**Mark** *the early years in London, my horizons were expanding in all respects. Had a good future to look forward to and that comes crashing in on you with an HIV diagnosis and you know that at some point you're gonna become very ill and die very quickly and very nastily*

## The awareness of not having a future

**Patrick** *You're in school talking about career options and stuff like that. What can I, can I do? I nearly died a couple of months beforehand and now the people were talking to me about career options*

**Mike** *Like when Jessica was born, I thought, 'you're not going to see her live. You're not going to see her fifth birthday and then you're not going to see her tenth birthday.*

## And this got worse.

**Haydn** *As the years progressed you would think that you'd become more at ease with it because you seemed okay but it didn't seem to work that way it worked in completely the opposite way, you became more anxious. Because you thought, 'right that's five years I'm counting something, it's got to be next year then.*

**Charles** *So, you're going through life without making plans.*

**Stuart** *I'm constantly being told that my life was gonna come to an end fairly sharp-ish. So I tended not to bother*

**Paul** *I never booked a holiday in advance, I never did anything like that. It was all last minute.*

## Some took this a bit far

*"I didn't ever start reading any big books" (anon - to avoid his embarrassment)*

## Some saw something liberating in this though

**Mick** *because of the fear of dying, I've had a more exciting and fun filled life than most people will ever have. Because we've lived life as in I'm gonna die so let's just do what we want and sod the expense or sod the repercussions.*

**Tom** *Because, yes, you scare yourself, and you have a few near ones, and things like that, but, there's the element of, did it matter? You know, it doesn't matter. So what? And my friends reciting to me, 'Now you be careful, you are going to kill yourself,' it didn't matter. So what? I'm dead anyway*

## But it didn't happen

**Gareth** *I think, you know, with all those things in place, I'd accepted that my time was coming. And, it didn't. They found a drug from America that they wanted to try; it worked for a few months, and I got well.*

## And to go back to the birth of Jessica...

**Mike** *... 'you're not going to see her live. You're not going to see her fifth birthday ...you're not going to see her tenth birthday.' And she was eighteen last week and I'm still here.*

## Still being here is not so easy though

**Catherine** *...I feel like I planned so long for something that never happened.*

**Suresh** *The sad fact is that my friends and I haven't prepared for tomorrow. Because we weren't given tomorrow, we were just given today and that was it, so we have not made any preparations but there will be a tomorrow because of the medication.*

**Haydn** *It took it seemed like eternity before I did start to think that that maybe I could plan next year ahead of us.*

## This should have been great news but...

**Mick** *I certainly got to the point of thinking, well, I'm healthy, I'm quite well. My CD4 and viral load's really good. I might not die actually, which is quite a scary thing when you've been living for so long thinking you're gonna be dead, and you haven't got to do anything, you haven't got to plan and think about retirement and all that.*

**Ian** *there came a point when you thought 'Oh I'm not going to die, what the hell am I going to do?' ... 'What do you do with this time? ... [We] had been used to idea that I wasn't going to be there and we struggled with something that should have been really happy, which was that there was a future. We had a future but we didn't know what to do with it.*

## But not all of us saw it this way

**Ben** *I made plans before and look what happened. When I was young like I said any achievement I seem to have made just got dashed on the rocks by some sort of illness. So when I was a kid I sort of gave up. I haven't given up on life it's like I've given up on a future.*

## But not given up hope

**Ben** *I wanted to learn to ride a motor bike. ... and I achieved that and I passed and I felt so happy for that I really was chuffed, cos it was about the first thing I'd achieved, well for myself; ... and then I got my bike licence... I just felt as though anything was possible for me now. If I had the right teacher I had the right state of mind then I could achieve anything I wanted.*

And even for the man who was wary of reading big books things have changed

*"I wouldn't have got married if I didn't think I'd got a future to look forward to." (anon)*



## Stop me if you think you've heard this one before...

Participating in these interviews was difficult and challenging for many of the interviewees. Recalling their life history raised very personal and painful memories and many of their experiences still have a deep reverberating effect today. Without a doubt the treatment for HIV infection has dramatically improved the life quality of those needing it and for the majority interviewed there is now a sense of a future being in front of them. The interview may have been about their past but the story is still unfolding - being asked to talk of memories which evoke pain and anger but which are still so much part of their lives. HIV is still there, almost all have Hepatitis C as well, along with a life long reliance on drug therapies and many are disabled from haemophilia. This story is still very much a living reality.

The interviews lasted between three hours and ten hours and covered a huge range of things as the different people described different important events in their lives. It would be impossible to cover everything that people talked about but here, in their own words, are just a few of things people talked about. Read on.....

### Ask me

**Dave** [The interview has] been quite easy actually; I thought it'd be a lot harder. And when I've been talking, I've just been thinking about the struggles and the ups and downs that I was going through at the time and, what an achievement it is to actually be still here now after all these years. And after everything that's thrown at you. So I should really pat myself on the back.

**John** Because [we're] not the type of people who can talk together, so really the tapes are important, because, who knows she can just put them in the recorder and play them back - hear my voice - even though she might not want to hear my voice at least it's there on tape.

### Panic

**Ben** Right well from that day onwards it's like a storm started that day you know. I know my life had felt pretty calm up until that point and then, from that day onwards and that night when mum and dad and my sister were there. It just felt like this massive storm had started in my life and there was no way of making it go away. I knew I couldn't make it go away...The only thing I could do was to deal with it. I was in a way I was like in pieces,

**Richard** When I was told, I was getting pictures of icebergs put through my door saying "This'll kill you!" People were frantic about it, it was a killer disease and that was it, and it was a gay thing and it was a drug thing, oh and it might be a haemophilia thing as an aside, but there aren't many of them so don't worry. It was just the whole, I mean, people are discriminated against now, but nothing like, you just wouldn't dream of telling people in those situations 20 years ago. You just wouldn't dream of it, because people were losing jobs, people were losing homes, people were losing families, you know. And people still discriminate, but it's hard to grasp if you weren't around or you weren't involved then how frightening it was. It was frightening because you thought you were gonna die, but it was just as frightening because you couldn't tell anyone

### Hand that rocks the cradle

**Charles** I was actually taken off my mother at the ripe old age of about five months old, and put into care, for no other reason than that I was a haemophiliac, and doctors, social workers at the time couldn't understand why I was in and out of the hospital with lumps on my head or anywhere else on my body, bruising. It was only once they took me off my mother, and I got a bleed in my knee, right knee, that I was hospitalised, they opened me up, i.e. the knee, and then, lo and behold I was a haemophiliac. But they still didn't let me

out of that place until I was seven... They thought I was abused. But once they found out, they never gave me back to my mother.

## **Suffer little children**

**Patrick** You're in school talking about career options and stuff like that. What can I, can I do? I nearly died a couple of months beforehand and now the people were talking to me about career options - Trying to balance a normal life of a teenager, you know a 16 year old with knowing that wasn't easy - See I just couldn't see the future really, I didn't have any plans or, any work to go into....it's hard because you look around and to see other people being so carefree - or at that time people were talking about careers and, what they do when they're leaving school. Just general life really and you're, while they're thinking about that, you're thinking about having to take the Dapsone pill, or, how bad it was a couple of weeks ago when you were lying in hospital.

**Paul** I had probably more stigma about that than anything else, because I didn't want anyone to know about that. It was like I didn't mind them knowing I'd got Haemophilia, or that I'd got the calliper, or that I couldn't play football but, I thought if my mates find out that I've got a teacher coming round to teach me maths as well in the evenings, I'm really going to have the Mickey taken out.

**Ian** There has to be some benefits of being a Haemophiliac - not having to play Rugby and not having to do metal work are the biggest ones.

## **I started something I wouldn't finish**

**Mike** Ten years ago, 1993, when I started an Open University degree, I honestly thought that I wouldn't finish that degree but I said, 'Nevertheless it's something to work towards and it will keep you going. And if you do finish it that's a bonus.'

**Suresh** So my aim was just to finish university, you know. Like I said, everybody, they were given three months to six months or whatever. Whatever the guidelines they were given, so I thought, as much as I can do in six months, I'll do. But then the six months lasted for a long time (laughing).

## **Still ill**

**Martin** We were probably the worst patients possible because, at Birmingham Children's, an hour after dinner you're supposed to go onto your bed for bed rest, curtains closed and what have you. Not the haemophiliacs, no, no, no, no. We spent enough time off our legs as it was, if we could get up and run around, we did! (Laughing). Yeah, I've got a lot of fond memories of that hospital. I suppose it's sad in a way, really, when you think of your childhood and you start reminiscing about times in hospital and things like that. But as a haemophiliac you do spend a lot of time, back then in those days, you would spend a lot of time in hospital. Now, thank God, because of the treatment, time in hospital for a young haemophiliac should be very, very minimal.

**David** We set up our own Haemophilia Society, mainly parents at that time, though I can well remember going in the hospital and two younger haemophiliacs, though I didn't realise they were haemophiliacs at the time, I was almost knocked down by a couple of wheelchairs, and I heard this sister say, 'That's those damned Lewis twins,' and they were the haemophiliacs. And they...and I met them, and they're old friends now. And, we set up later the first Birchgrove group together.

**Mick** I was told in no uncertain terms, I was asked, not to talk about my HIV status whilst sitting in the waiting room of the haemophilia clinic because it upsets other



haemophiliacs. So you just didn't. I used to sit there.

**Paul** So all about this new wonder drugs here Factor Eight's here it's great, in many ways it was and it would have been if they'd made it from clean blood, and that's my bottom line. I haven't got any arguments about Factor Eight ever been invented, or ever being used, it was what they made it out of. It's like coming up with a fantastic invention for a brand new recipe for a cake, but you go and use a load of bad eggs to make it, and that's the analogy I tell people when I explain Factor.

### **This night has opened my eyes - ( with the 'nancy pancy' Birchgrove lot)**

**Mick** it was '94 or '95, we had a letter through the post from Birchgrove. Never heard of this Birchgrove before in my life. "Come and join us on our help weekends" and nancy-pancy and "Let's have a chittety-chat and meet others in your position" and I thought, I ain't going to that crap! Anyway, she dragged me there, kicking and screaming, to Manchester. It was just unbelievable, it was an eye opening experience to sit there with 30, 40 other haemophiliacs who were thinking and feeling and saying exactly the same things that I'd been thinking and feeling but weren't saying to anybody else. And it was just, it was nice to know that there were other people out there who felt as pissed off, angry, depressed, whatever about the situation, and I wasn't just on my own and loopy. And it was okay to laugh and joke about it.

**Suresh** And it really was, like I said, an information sharing exercise where people really benefited and they felt empowered to look after themselves and feel that there was life at the end of the tunnel. Just because a few people had passed away, doesn't mean that you're, there wasn't a number and you weren't the fifth, the sixth on the list, you know. And if you were on the list then it wasn't gonna be tomorrow, it might be later on so let's make the most of it, and people were given that sort of energy to carry on and make the most of what they had. And Birchgrove have done wonders for the HIV haemophiliac because without their organisation I don't feel that people would've delved deep in their psyche to say well, yeah, I really can look after myself.

**Catherine** and you can just spot the other HIV positive haemophiliacs there, you can just spot them, because they're getting pissed and they're trying their damnest to have a good time, because at last they can actually talk openly about this thing, which is crippling them. As opposed to the physical problems, which are crippling them

**Mike** I dread to think where I'd be at mentally if I hadn't met people like Paul and Martin and Gareth. I'd dread to think where I'd be in terms of my medication, where I'd be in terms of my attitude towards the medical profession.

### **Cemetery gates**

**Gareth** dealing with deaths on a regular basis in the early days, you're just going up and down all the time, your emotions are being ripped apart constantly, you know, and the friends that you make, especially in Birchgrove, you're working with people constantly, the friendships are amazing, because of where they come from and, certain people I've met through Birchgrove, I would never have met in my walk of life, you know, there's no way we, our paths would have crossed. And I feel a much better person for meeting those people.

**Richard** I'm angrier now than I was then. But then I suppose I'm not as scared now so it's easier to be angry,

**Mike** As I said my preconceptions of what an AIDS victim was, was being a victim. I'm going to use that word deliberately because I didn't know anyone apart from myself and my --- the reality of AIDS was me and my brother. What the media was telling me were these pictures, these images of guys with Kaposi's sarcoma or PCP and wasting illnesses that you get. And so I just couldn't relate to that and then when I see these guys and sitting there in a pub with them and drinking pints of Guinness and swapping, bullshitting each other essentially and it was so different to what I expected.... And it just felt that suddenly this part of your life that you had compartmentalised and put in that box, suddenly it was okay to open it and bring it out. But you were in control of that, you are the one who were deciding what to share with these people.

### Girl afraid

**Tom** So we're sitting round peacefully with, you know, glass of, a glass of beer, and candles going, and, you know, a nice romantic evening. And she hugs me, and tells me that things can be different now, because she's had a coil fitted. After I've finished with coughing and wheezing and wiped the spilt beer off my face and neck, I don't know what to say, because she now wants to have unprotected sex. So what do I do? The only thing I can think of, the first thing that springs to mind, is, I carry on drinking, but in a much more determined manner. So that within the next hour or so I'm fairly well pickled, and I manage to start an argument, and simply leave. And that's the end, that was the end of that one.

**Dave** It affected [teenage life] really badly to be honest, because I never really got into the whole sex aspect of college or like normal people do, because I was so paranoid that I was going to pass it on to anybody else, with the adverts that they were promoting on TV at the time. So it made me quite nervous around people. I was paranoid about passing someone like a can of coke when I'd been drinking it, in case they caught it. Sharing stuff, sharing a packet of crisps, sharing sweets the whole thing, I was just paranoid. And it went through a stage of planning my own funeral, what I was going to wear, who was going to be there. The whole scenario I went through, went through it for months I just wore black most of the time when I was at college. I suppose it was just like my mourning time to do, I was just mourning my own life at the time but I soon got a kick in the head then. And I've been fine ever since.

**Derek** So I told her. I told her I was a HIV positive... and her basic reaction was, 'Is that all?' she said 'I thought you were gay or something.' And she said, 'Was that all?' and that was amazing, she just, she didn't care about it, and that was such a relief. That was an amazing night. We were married in March '92. Bit of a rush, some people might think, but we never looked back.

**Paul** All my mates were out having a great time. You know at the age of 21, 22, 23, I was living a life of a monk.

### Interesting drugs

**Richard** As far as HIV goes, I feel pretty good. I've been on the combination therapy for only 14 months. I was very ill before I went on it, but I'm not now. I do get side effects, which aren't nice. It's summed up to me by, someone said, they were talking to a young boy, well not a young boy, I suppose he must've been about mid 20s, and he said, "Every time I look at my cabinet with pills in it, it reminds me of what I've got and I feel sad and depressed", which must be every day of his life. And my mate who told me this said... "Well every time I look at mine I think they're keeping me alive", and that's what I do. I take my pills every day and although I have side effects and I don't like going to the



hospital, I appreciate the fact that if I lived in some parts of Eastern Europe, African countries, Indian countries, China, wherever, I probably would be dead by now.

**Joseph** What I did find, oddly enough, was that for the year that I was on interferon and then interleukin-2, my haemophilia was absolutely fantastic, it was well controlled, very few bleeds, and when I had bleeds they healed extremely quickly...And, I've got to say, that was a completely new and motivating and invigorating feeling. And, I was just praying it was going to last. Unfortunately once I'd stopped interferon and ribavirin, the effects didn't seem to last, I went back to my normal cycle of haemophilia with bleeds and, and so on. ....My CD4 count when I started was around about, around about the 300 mark, and, after I'd had five cycles it was up at around about the 750 mark...

**Martin** I had my first course of treatment and I don't know whether you've heard about Interleukin but it can be pretty horrendous. The very first dose was like the highest dose they gave me and I was pretty rough with it. I had all the side effects, I think there was about 16, and I had the lot! But the plus side was, when I went back to the hospital, my CD4 count went up to 1300 and the psychological effect of that was just unbelievable! I felt like Superman.

**Paul** After three weeks, four weeks I started to notice a huge change, I was surprised, it shocked me how rapid. I suddenly started having vitality. I was eating more, in fact, I was actually having an appetite. Not only was I having an appetite and eating but I was managing to keep it down, and not see it five minutes later down the toilet pan. It was odd, I started going out, I started having my appetite for alcohol came back and, I started enjoying going out, I started being a lively person.

### **What difference does it make?**

**Derek** I find it very hard to change a lifestyle that I enjoy...because of something that doesn't affect me.... Why am I okay.? Why has HIV never taken off in me and it has in all my peer group? Why is it that everybody I know on treatment and I'm not? And I believe there are a couple of other treatment free people around but I haven't met any. And Hepatitis C hasn't caused me any damage yet much, so what is it? And then you think, 'Is it? Is it my lifestyle? Is it something that I'm eating, drinking, smoking? It sounds crazy and it's working, I'm not going to change my lifestyle just in case, just in case it changes something else and sets things off, which is a pretty weak excuse to carry on drinking and smoking I know but, those are the thoughts that go through your head.

### **Frankly, Mr Shankly**

**Gareth** football has been the one constant in my life, and I think constance and continuity in HIV, haemophilia and AIDS care is, is crucial. And that football, no matter what else have happened, divorced, houses, this virus, that virus, every other Saturday, me and my friends will be at the football, have a couple of beers, and whatever, and, no matter what goes on, I know... And some of the people we go to football with are nothing to do with haemophilia or HIV, they're just a group of people who met down the football, sit in the same seats, and we've become friends, and, and that's a constant.

### **Is it really so strange?**

**Martin** This was in 1988, I was playing for a pool team in south Derbyshire and I'd been playing for that pool team for a good number of months and then I walked in there one Thursday night, and the landlord says, we don't want you in here, the locals don't want

you in here. I was 19 years old, you know, I was – made me feel so empty and just thinking, oh, I just wanna die, wanna curl up and die! And I came home, but within half an hour of me being back at home, another pub which was a 100 yards down the road from the one that kicked me out, they heard about it. I don't know how, but they phoned me and they said, look we've heard what happened, we want you to come and play pool for us. Totally different attitude, just down the road. And it's those little bits that just restore your faith in humans. Somebody's there ready to kick you down, but there's always somebody there to pick you up again.

**Derek** I've been very, very lucky. I've had fantastic support from the people around me. And before I met Margaret nobody knew, I wouldn't tell anybody because of possible stigmas, but when Margaret got to know me she said, 'I can't keep this a secret,' and to be honest what once, now I've got Margaret, I don't care who knows. And we have told a lot of people and, everybody's been great, fantastic. I've even had letters from the director at Kew giving me support and things, I think that was really nice.

### **There is a light that never goes out - (The Woodland Grove)**

**John** It'll take 50 or even a 100 years or even more, but eventually it'll be a woodland and people can go and enjoy their picnics and children and grandchildren if they're told about their grandparents that have died, 'Oh this is where granddad died and this is the tree planted in his memory'. That's good.

**Paul** The only thing I actually feel content about what I've done, was being involved with the Birchgrove Woodland Grove and Swindon, because when I became involved with Birchgrove, the wood was planted in '96, 1200 trees were planted on a Woodland Trust site. It's a huge forest and we've just got a small corner of it, but there was nothing telling people what it was about and where it was and I thought this was so sad. A lot of the guys originally involved in it, had passed away and - it was like an unfinished project to me and I wanted to continue with it, and I took it on, and it was hard work, a few guys that I was involved with gave me some support, and we did some fundraising and we finally got permission from the Woodland Trust, and a lot of wheeling and dealing with them and, we've now had erected a three-tonne boulder in the centre of the wood that's inscribed and it'll be there forever. It's a Standing Stone, it's in the county of Wiltshire, where lots of Standing Stones lie, it fits in naturally with the environment and nobody can miss it. And I'd like to think that even if I die tomorrow, I was extremely instrumental in that stone being placed where it's placed, and I think it's the most worthwhile thing I've ever done in my life.

### **Death at one's elbow**

**Ian** Ten years ago I thought I'd be dead within two years. Ten years ago I was not treating myself with a great deal of respect. Ten years ago I had a fantastic relationship, which I don't think I would have been able to sustain and ten years ago I was becoming less of a person. Oddly now I see my life in terms of all kinds of opportunities I'm always doing something, doing something new. I've met the most tremendously inspiring people, as I said. I'm beginning to think about things like 'what am I going to do when I retire?

**Ben** I'm not going to die now, I'm going I really but now I believe I'm going to live to a pretty good age you know...I've already, I was always saying I wanted to get to twenty-one. I'll be twenty-seven in March, what's it October now so, you know I don't get ill any more. If I get ill now it lasts five, six days. My friends will be ill for like two weeks. How do you work that out? I'm supposed to be the one with you know HIV and I'm healthier than they are.



**Catherine** I was just very needy, very desperate, very angry young woman, who was going to rebel against everybody and anything that came in my path. And I had a mini-van like I say that had a carpet in the back, and it went ninety-two, that's how much it had on the clock, and that's how fast I went everywhere. And I was just challenging life to come up and kill me. 'Come on I'm going to prove it you can.' And I just went round the angriest young woman ever in that time.... I wanted something to happen rather than this waiting and wondering and questioning. 'What is going to happen? What's round the corner? What's going to get me? I'll go out and meet it.'

### **Money changes everything**

**Ian** I've always held fairly strong views that compensation possibly doesn't help a lot of people. And that particularly the kind of compensation that we've had, which has been tied to need and medical need and that it discourages people from being healthy and discourages them from taking an active and healthy role in life.

**Suresh** Haemophiliacs live in a cuckoo world really. We just believe that whatever the health service gives us is the maximum amount of information or service that we have at our disposal. So if they didn't offer any phone numbers or if they didn't offer any extra facilities or services it's because they honestly weren't there. We never gave it a second thought that, you know, this is what the haemophiliacs had but it's the similar to what the gay community were suffering at the same time and HIV for them was the same as HIV for us and the services they were entitled to were the same ones that we were entitled. Because the hospital never actually gave us that information in black and white we just assumed that it wasn't for us, it was just for them.

## **What happens now?**

The archive itself is now set up and you can go to the British library and listen to the tapes of peoples' life stories as well. For those of you that do not know the British Library is next door to St Pancras Station in London on Euston Road. You can also look at the National Sound Archive catalogue on the British Library website at

<http://www.bl.uk/collections/sound-archive/cat.html>

You can search the catalogue for "haemophilia and HIV" or by its catalogue number of C1086. Here you will find details and summaries of the recordings of the people who took part in the project. The findings will now be analysed by the research team and will be presented at a number of medical conferences over the next couple of years. We hope to discuss the findings with medics, oral historians and the public at conferences and events in Britain, Australia and Canada and have already presented initial findings at the XIII International Oral History Conference in Rome. We are in the process of having a website designed that will feature a selection of quotes from people who are happy with them being available on the web and intend putting things together for a book.

This year is also 20 years since people with haemophilia were tested for HIV and, some, were informed of their diagnosis. We hope that this important milestone is marked by some of the British HIV agencies during World Aids Week this year and we will be offering our findings to them. We also hope to start a new project, which you can read about elsewhere in this edition of Birchgrove.

**Krista Woodley,  
Wendy Rickard,  
Robert James and  
Siân Edwards**



## History lesson and background to haemophilia and HIV

in case you were not one of the ones living it at the time...

The history of people with haemophilia and HIV is a succession of medical triumphs and disasters, and had never been told by the people who experienced it before. Haemophilia treatment over the past 40 years has been a roller coaster ride of an amazing medical success which then became the route of transmission for a series of terrible diseases. In 1960 when there was no treatment life expectancy for people severely affected by haemophilia was below 20 and meant a succession of painful bleeding episodes crippling of the joints which was ultimately fatal. With the invention and use of cryo-precipitate, a precipitation of human plasma, the first effective treatment became available. In the following decade this treatment was refined into a clotting factor concentrate made from multiple blood donations and treatment at home became available, encouraged and avoiding the need for weekly or daily hospital visits. This revolution in treatment permitted people with haemophilia to treat themselves for their bleeding episodes or be treated by their parents or spouses. People were taught to give intravenous injection of the factor concentrate themselves and so liberated them from continual reliance on hospitals. Prophylaxis was available through some advanced hospitals as an attempt to prevent the bleeding from starting and protect the joints from the resultant damage. For the first time people with haemophilia had the chance to go to mainstream schools and work.

In 1981 the first person with haemophilia died of pneumocystis carinii, a form of pneumonia peculiar to people with severely damaged immune systems. During the next ten years over 1200 people with haemophilia in Britain and many thousands around the world were diagnosed with HIV. Over 300 died in the UK in the first 10 years of the epidemic. During this decade people refused to send their children to schools attended by those with haemophilia, university departments would not register students with haemophilia, families were forced to leave their homes after attacks, some health care workers refused to treat people with HIV and the only treatments available were palliative. People with haemophilia who had had life expectancy dramatically extended by treatment now saw it massively shortened as a result of that treatment. In 1991 the prolonged legal battle against the UK government finally ended with an out of court for settlement of between £20,000 and £64,000 per person in one of the first acts by the new Prime Minister, John Major. In England and Wales the agreement was on condition that the recipients waived the right to future litigation against the government regarding any previous or future infections in blood products. That year a test for hepatitis C became available and those still alive were all informed over the next few years that they had been exposed to another potentially fatal disease. Before the widespread use of an effective treatment for HIV in the mid-nineties the death toll had passed 600, over half of all those infected. As haemophilia is a genetic disorder predominantly affecting males many of those infected helped care for their own brothers, uncles, and cousins when they died.

Between 1995 and 1999 the death rate plummeted as combination therapy for HIV proved successful for most people. A second great medical advance had dramatically impacted on the lives of people with haemophilia and left them to contemplate a future once again. Blood products are much safer now utilising viral inactivation techniques, however, parvovirus has been shown to evade some filtering procedures and last year many people with haemophilia were informed that treatment they had received had been made with blood donated from someone who later died of vCJD. By the year 2000 more than 800 had died including over 100 from liver disease. The 400 still living have not only lived through dramatic history but are still faced with the challenge of managing their haemophilia, two chronic infections and the complexities of multiple treatment regimes.



# Plans for a new project 'HIV in the Family'

## Plans for a new project 'HIV in the Family'

**'I just hated people asking him 'What do you want to be when you grow up?'  
Only I knew he wouldn't grow up.'**

*(Mother of Jamie, diagnosed in 1985 with HIV, six years old)*

Brighton University is applying for funding to create an oral history archive in The British Library of interviews with the partners and parents who were significant in the lives of those people who were infected with HIV through the use of contaminated blood products in the early 1980s.

What has emerged from the Haemophilia and HIV Life History Project is 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 wives, partners and parents, witnessed their loved ones and their children face the challenges of living with HIV infection, or were present as many of them died. A number of the partners became infected and have had to deal with their own HIV as well as the complications of their partners medical conditions. We have been approached by wives who cared for their husbands and we have been approached by mothers whose sons died when they were very young. All feel passionately that they have a story that should be told.

For the 800 adults and children infected with HIV through blood products who have died we need to turn to their parents and partners in order to hear of their life experiences. For the 400 still living, the experiences of their parents, partners and children on what happened will add a significant dimension to any work on the life stories already collected and ensure a much wider perspective on this tragedy is available for future generations

This project is in the very early stages and funding applications have not yet been submitted. If successful the project team will be looking to interview wives, partners and parents of people with haemophilia and HIV. The hope is that once funding is received interviews will start in 2006. If you are a partner or parent of someone with haemophilia and HIV infection and would like to be involved in this project 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)**

**Birchgrove would like to thank all those involved in the Life Histories Project, and for the contribution to this newsletter. You have helped us tell our story and are now part of it.**

**(We would also like to take this opportunity to apologise for "The Smiths" references in this edition. Heaven knows that some of us are miserable enough already.)**

## Men Only

Nottingham Friday 13th- 15th May

An event for male registrants of the MFT.

## Haemophilia Society AGM/ Conference

This annual event will take place in September, but at time of going to press details have not been confirmed. Check out [www.haemophilia.org.uk](http://www.haemophilia.org.uk) or *HQ* magazine if you are a subscriber for forthcoming details.

## Women with HIV

A weekend event for women who live with HIV will held during 8th and 10th July. The location has not yet been confirmed but details can be accessed by contacting the MFT 020-72330057.

## Glasgow Weekend

9-11th July- Held at the Radisson SAS hotel in Glasgow this event is for registrants of the MFT and their partners who live in Scotland, Northern Ireland and Eire. If you are interested in attending please contact Roz at the MFT 020 78081170

or email [admin@macfarlane.org.uk](mailto:admin@macfarlane.org.uk) or [richard@macfarlane.org.uk](mailto:richard@macfarlane.org.uk)

## UKCAB

The UK CAB (Community Advisory Board on HIV) meetings are now booked for the following dates:

Friday 3rd June, Friday 19th August, Friday 25th November

All the meetings will take place at the Medical Research Building at 222 Euston Road.

You can now register for the June meeting by visiting our registration page:

[www.i-base.org.uk/ukcab/regform.html](http://www.i-base.org.uk/ukcab/regform.html).

*The UK CAB meet quarterly to discuss a wide range of treatment issues and is represented by a variety of UK wide HIV patient led organisations, support networks and information providers. At present there is no representation from people living with haemophilia and HIV at the meetings. If anyone is interested in attending please get in touch.*

## National Long Term Survivors Group

NLTSG is a self help group specifically established to meet the needs of those who have been diagnosed with HIV for 5 or more years. The group's main aim is create opportunities for individuals living with HIV, across the UK to meet for weekends in a safe and secure environment.

As most of Birchgrove's HIV positive readers have now had 20 years of diagnosis, we are no doubt eligible for the criteria to access NLTSG services.

If anyone is interested in please get in touch with NLTSG, BM LTSG, London, WC1N 3XX.

[www.nltsg.org](http://www.nltsg.org) [mail@nltsg.org](mailto:mail@nltsg.org)

Dates for NLTSG weekend retreats are as follows:

2005- 1-3 April, 8-10 July, 16-18 September, 16-18 December.

2006- 7-9 April, 7-9 July, 15-17 September, 15-17 December.

For enquiries and bookings contact Tom Matthews on 0121 6899520 or [tommatthews@blueyonder.co.uk](mailto:tommatthews@blueyonder.co.uk)

## MFT Partnership Meeting

The next meeting of the Partnership group is to be held on Monday 13 June 2005 - **Venue to be announced**. Open to registrants of the MFT. Please contact Roz at the MFT if you are interested in contributing.



# Snippets and Briefs

## **Rumours and Rumblings at the MFT.**

There has been much concern about the Macfarlane Trust, which has escalated over recent months. Most of this concern has been regarding changes in operations and staff positions at the MFT and how they are affecting registrants.

In March Peter Stevens, Chairman of the MFT, wrote to all registrants outlining the MFT's position. This was in response to a circulating petition letter amongst some registrants, who wanted answers to their questions.

Peter stressed that this petition letter was based on rumour rather than fact and wrote to registrants in order to quash any "unnecessary alarm and anxiety".

The MFT are planning to improve communications between the MFT and registrants through more frequent newsheets and public meetings. They are still making changes resulting from the Long Term Review which will take time to implement.

Representation of Registrants views was a topic and it was identified that there was still a vacancy for a User Trustee. This post has to be applied for via the Haemophilia Society.

The MFT have stated that the position of the Regional Support Workers (RSW), when in place will help to eliminate problems of bureaucracy, be more accessible and be able to help personally in registrants dealing with the MFT. Peter said that this would not mean that you have to meet your RSW or have a home visit, or their involvement will not be a condition of applying for grants.

He also reinforced that the MFT has no plans to introduce Means Testing to regular payments and that there are no plans to change the system to reduce the levels of regular pay. However he did acknowledge that payments at present are linked to income support entitlement and family commitments, which are in themselves means tested.

The National Support Services Committee (NSSC) meet as a sub committee to decide on Single Payment grants. All grants have to have evidence of expenditure, which is an area most registrants will be familiar with. Peter said that this is not a new rule but indicated that it just wasn't being done in the past. (word of caution though –only send in photocopies as your guarantee is worthless if the MFT lose your originals). Anyone can appeal against decisions via Jude Cohen at the MFT if they are not happy with decisions, and if registrants are still not satisfied their appeal will be considered by the full board of Trustees. Peter did not say how long this process could take though.

The issue of loans was brought up and the MFT's position is that registrants can apply for loans, in situations where the MFT do not feel a single grant is appropriate. The MFT have a limited budget and have to decide amongst competing requests so you cannot demand, insist or expect that you will receive the funding you requested, just because you have a genuine need.( Birchgrove have also been informed that loans are subject to an arrangement fee payable by the registrant. If this is true, and not a rumour, then this needs taking up at Partnership meetings)

Also help for the bereaved has seen no change to its support.

The Trust is in the process of compiling a case for further funding from the government for the period 2006 onwards as the current funding, which is not meeting registrants needs, will not be expanded. Jude also recently sent yet another questionnaire to registrants asking information relating to our health related living costs which registrants should have received. Peter and Martin Harvey have offered to speak to anyone personally if they have any concerns they would like to discuss (Tel 020 72330057)

## **MFT Web site and Bulletin Board**

The confidential MFT Bulletin Board for registrants of the trust is being widely used and has a number of threads of different topics for users to read or respond to what takes their interest. The diversity of the threads include US Litigation, Freedom of Information Act, DWP fraud Squad investigations, EDM's, Legality of sex, health tips such as Lipoatrophy and body fat redistribution and even a jokes section.

The MFT website also features News, Member Utilities, Forms for feedback, trust information, All the Trusts Newsletters in pdf, sections on Financial Assistance, Staff and Trustees, Welfare Benefits as well as the registrant only Bulletin Board.

To use the Bulletin Board you need a password, which can be obtained by contacting the MFT. Once on the site you can change your password and use the Bulletin Board or the Chat Room facilities.

Contact MFT 020 78081170 Email [admin@macfarlane.org.uk](mailto:admin@macfarlane.org.uk) [www.macfarlane.org.uk](http://www.macfarlane.org.uk)

# — Snippets and Briefs —

## **Haemophilia Society Web site**

There is also the opportunity to discuss general haemophilia issues with other people who live with haemophilia, on the Haemophilia Societies Web site discussion board. Topics include Ask the Society, US Litigation, Hepatitis C, Co-infection and Financial issues. The web site also gives downloadable publications and research and gives information on accessing services such as the Telephone Support Network

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

## **Recombinant for All**

As from this April 2005, Recombinant clotting factor should be available to everyone in the UK regardless of age. This move has now come when English patients over the age of 40 have been denied access to this safer and essential clotting factor option.

The financial year beginning April 2005 will see the last phase of the roll-out of recombinant clotting factors to all patients for whom recombinant is a viable treatment option. This includes adults with haemophilia A and B, children and adults who have developed an inhibitor to factor VIII or IX, and anyone with the rare factor VII deficiency.

The funding should be in place from April for all remaining patients on plasma-derived treatment to make the switch from plasma treatment to recombinant if this is their wish. The only delays that anyone should experience are those of clinical expediency or using up individual stocks of plasma-derived treatment.

Anyone experiencing problems may contact the Society helpline (0800 018 6068 or [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk)).

## **US Litigation**

On the 2nd March Lief, Cabraser, Heinmann and Bernstein LLP issued an update to its clients on recent developments. This communication was distributed also by Denis Whalley of Anderson Eden Solicitors to clients registered with him. If anybody has any concerns about this and are not in touch with the US Attorneys please contact Denis Whalley or Lynne Wilson on 0870 8879105 or email [lynne.wilson@andersoneden.com](mailto:lynne.wilson@andersoneden.com) [www.andersoneden.com](http://www.andersoneden.com) [www.lchb.com](http://www.lchb.com)

**LCHB will be in London in May on unrelated business and have suggested setting up a meeting with UK clients on the 21st if there was enough interest, and to give people an opportunity to raise any concerns and get a clearer explanation of progress. Details of this meeting will be posted on the MFT Bulletin Board, or via Denis Whalley if the meeting goes ahead.**

## **HIV i-Base Treatment Guides.**

There are now three new revised editions of the i-Base treatment guides, which are available in pdf file, in html on the website, and in print format.

The treatment guides homepage is: [www.i-base.info/guides/index.html](http://www.i-base.info/guides/index.html)

And for the pdf download page: [www.i-base.info/about/downloads.html](http://www.i-base.info/about/downloads.html)

Recent changes have been to **Guide to Avoiding and Managing Side Effects, Changing Treatment: what to do when treatment fails and HIV, Pregnancy and Women's Health**

HIV i-Base publish HIV Treatment Bulletin, Positive Treatment News (PTN), and non-technical Guides. All publications are provided free by individual subscription or in bulk for use in clinics.

HIV i-Base, 3rd Floor East, Thrale House 44-46 Southwark Street London SE1 1UN

T: 020 7407 8488 <http://www.i-Base.info>

## **Liver Transplants in HIV+ patients**

Recently published guidelines for Liver Transplantation in Patients with HIV Infection are available on the BHIVA website ([www.bhiva.org](http://www.bhiva.org)) in pdf and Word format.

This document was published in April 2005, following a consensus meeting of specialists in the field of HIV and Liver transplantation in June 2004. It was written on behalf of BHIVA and the UK and Ireland Liver Transplant centres and endorsed by the British Transplant Society Standards Committee.



## **Goodbye Christine - 1 in a 1000**

Birchgrove would like to acknowledge the retirement of Professor Christine Lee from the Royal Free Hospital. Prof. Lee has been working in Haematology for many years and if you weren't one of her patients you may remember her from Haemofact's, an information series of booklets published and distributed by the Haemophilia Society advising people with haemophilia on treatment safety in the mid 1980's.

Birchgrove managed to dig this gem from the archives and thought it may prove interesting reading in the circumstances.

### **Haemophilia Society - HAEMOFACT**

**A.I.D.S. - Release No 3 - 11th May 1984**

**(This factsheet contains important information concerning ACQUIRED IMMUNE DEFICIENCY SYNDROME)**

### **ACQUIRED IMMUNODEFICIENCY SYNDROME: AN UPDATE:**

The occurrence of acquired immunodeficiency syndrome (AIDS) in haemophilic patients has strongly suggested transmission of the disorder by blood products and epidemiological studies have suggested it may be related to a transmissible agent. Recently it has been reported that a retrovirus, which may be associated with AIDS, has been isolated at the US National Cancer Institute. Similarly, in Paris, a retrovirus has been isolated from the lymphocytes of a patient with haemophilia B who had AIDS. These reports should be received with optimism. The obvious benefits from such findings would be the provision of a blood test for both affected persons and donated blood - and in the long term, the development of a vaccine.

**In Great Britain the number of haemophiliacs who have been reported with AIDS remain at 2. Thus the incidence is less than 1 in 1,000 patients at risk.**

The relationship of the immunological abnormalities found in many heavily treated haemophiliacs at centres throughout the world is uncertain. However, it is now clear from studies in Scotland, Australia and America that these changes occur whether the plasma source used for the concentrate manufacture is volunteer or commercial.

It is possible that the immune suppression produced by repeated exposure to clotting factor concentrates lowers the threshold for infection with the putative AIDS agent. There is evidence that different clotting factor concentrates have a correspondingly different propensity to induce these changes. This is a function of the characteristics of the final product and the fractionation methods used to make it.

**The prospects for resolving these problems are brighter for haemophiliacs than for other high risk populations since improvements in plasma fractionation are likely to make it possible to remove or inactivate causal agents from therapeutic products. The heat-treated clotting factor concentrates which have been manufactured by many commercial companies and the NHS may be an advantage in this respect.**

*Finally, THE REALLY GOOD NEWS, is the announcement from the Royal Free Hospital, Speywood Laboratories and Genetech, San Francisco, that the gene for Factor VIII has been cloned and the Factor VIII has been synthesised in mammalian cell culture. Provided this can be successfully scaled up, which may take several years, synthetic Factor VIII would be available for use by haemophiliacs. Clearly this would provide a hepatitis and AIDS free therapeutic product.*

### **C. A. Lee. Senior Registrar. The Katharine Dormandy Haemophilia Centre (1984)**

Well as we know from history and the testimonies in this edition of Birchgrove, 2 Haemophiliacs with HIV turned out to be over 1250 by the following year, 1 in a 1000 at risk turned out to be 1 in 3, prospects for people with haemophilia were far from bright with over 900 deaths, HCV infection and CJD concerns, and the several years before we can all access synthetic concentrate has only happened in England this month, 21 years later.

We hope for your sake Prof. Lee that your pension forecast was more accurate.

# Snippets and Briefs

## Future of Birchgrove

In the last edition of Birchgrove we gave people an opportunity to feedback to us on our plans for winding down Birchgrove as a newsletter. Reasons were given in the last issue but these were mainly due to the changing times and changing patterns in people accessing relevant information and support. The MFT Bulletin Board and Haemophilia Society chat rooms now give people an opportunity to communicate with others. Most information is accessible by web sites and organisations that did not exist when Birchgrove was conceived.

We had 2 replies, one saying that he really enjoyed his Birchgrove read and he would miss it, but has no time to take it on, and another from a reader who has asked for a general meeting.

If we have no more suggestions or offers of taking this forward, the next edition of Birchgrove will probably be the last as we have now got to know it. We hope to launch a web site by the next edition, which we see as the way forward. We would like to thank all of our contributors, all our readers and all the people that give their support and have given their support over the years.

## The Woodland Open Day DVD

Many thanks for the comments that we received regarding the DVD of the Woodland Open Day sent in the last issue. Comments ranged from awesome, moving experience, thanks and appreciation, it made me cry, this should be on national TV to "I haven't got a DVD player".

We would especially like to thank the Grampian Haemophilia Group in Scotland for their donation towards the DVD. Although we didn't specifically request any donations, the DVD did cost more than originally expected with posting and this contribution was very generous and appreciated. The Grampian group showed the DVD at one of their group meetings and as well as finding this an emotional experience also found it to be educational.

Here are a couple of the replies we had:

*Dear all at Birchgrove,*

Many thanks for sending me a copy of The Woodland Grove Official Opening DVD. It was very moving and full of Government ignored home truths. Well done to all who took part including those no longer with us.

Yours very sincerely,

*J. D.*

*Dear Birchgrove*

Thank you so much for sending the video of the opening of The Birchgrove Woodland Grove. I have just watched it and I felt moved and full of memories of my husband who died in 1987. I hope to make the journey to the woodland site some time, so that I can see and feel the stone and the trees. With many thanks for the vision of the founders of this project.

*P. W.*

There are a small number of surplus DVD's, which Birchgrove have offered to give to the MFT to pass on to their bereaved contacts if they wish. If you did not get a copy and you would like one please contact Birchgrove with your postal address at [birchgrove1@hotmail.com](mailto:birchgrove1@hotmail.com). If you have not got a copy of the "Woodland Special" newsletter that gives maps and specific information about the woodland please contact Birchgrove for your free copies, as we still have a limited number spare.

## Travel Insurance

Rothwell and Towler's world wide cover policy for people with Haemophilia and HIV has now changed. They are still offering cover for HIV, HCV and everything else we have, but for the Haemophilia, new policy holders have to register with another company and pay an excess fee.

Rothwell+ Towler are happy to explain the changes. (Tel 01404 41234 [info@rothwellandtowler.co.uk](mailto:info@rothwellandtowler.co.uk)).

Birchgrove would like to hope that these changes have not been due to one of its editors having 2 cerebral haemorrhages in 2 different continents, spending 2 weeks in a Canaries hospital, 2 weeks in a Florida Hospital, having Air Sea Rescue Helicopter trips and a total of 3 teams of paramedics fly him home on special chartered flights.

*(Birchgrove would like to thank R+T's policy for getting him home safely.)*



## Haemophilia Society

First Floor  
Petersham House  
57a Hatton Garden  
London  
EC1N 8JG  
Information, advice and support.  
Admin: 020 7831 1020  
Fax: 020 74054824  
**Helpline: 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](http://www.positivelywomen.org.uk)

## Hepatitis Resource Centre

Tel: 020 7378 5496  
Email: [admin@hepccentre.org.uk](mailto:admin@hepccentre.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@akitanet.co.uk](mailto:andrewb@akitanet.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](http://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](http://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.  
Lawrence House.  
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Hulme.  
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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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**Life Histories Feedback Event at Swindon**  
where contributors had a chance to meet  
and share their experiences.

**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...**

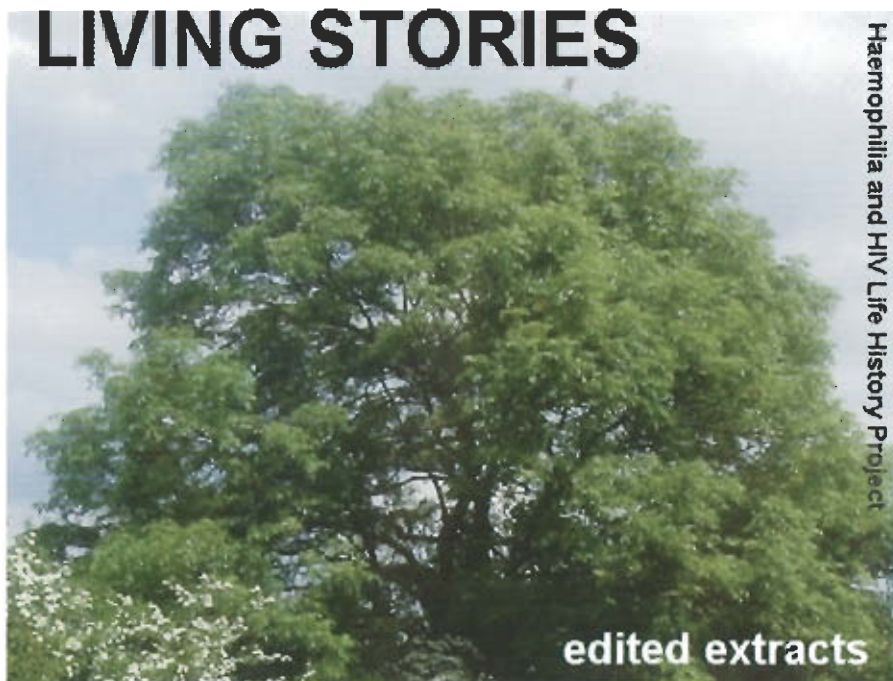
Can be empowered and  
enabled to deal with HIV/AIDS  
through relevant information  
and mutual support.

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.

## **LIVING STORIES**



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**AWARDS FOR ALL**  
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