

THE BIRCH GROVE

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ISSUE N° 4

THE PAS INTERVIEW - WASHES WINTER

When the Birchgrove Group discovered that the Macfarlane Trust was willing to undertake research into the needs of its registrants, we began waiting with eagerness and anticipation.

We have always advocated that the needs of those involved and living with haemophilia and HIV are many and varied and we have always felt that the provision has been random and at times limited. We were pleased to discover that the Macfarlane Trust had decided to use an independent body to carry out this "needs-led" research, and we were happy to participate in talks with PAS, the research company carrying out the survey. We gained the impression that the research company were aware of the complexity and the sensitivity of approaching Macfarlane Trust registrants. So it is with not a little disappointment, that we have become aware that this research may not be as competent as we had hoped. We have received a number of reports about the initial PAS interviews, and this is the

basis of one of them:

I was offered an interview with PAS and I was keen to take the opportunity to help in the research. I attended my local haemophilia centre at the appointed hour and prepared to undergo my ordeal. The interviewer was very pleasant and tried to put me at my ease, despite the microphone and tape recorder I was determined to be relaxed and honest. The first question was a bit of a corker "How did you feel when you were first told that you had HIV?" there are many ways to answer that question and few of them are polite. I began to feel like the victim of a car accident being asked "How was that for you?"

I gradually began to feel that this was her first interview for this survey and that she had little or no background understanding of HIV, let alone haemophilia and HIV. Oh well, I thought I'll just have to be more informative and more direct. The questions that she had to ask weren't exactly searching or exploratory I suspect that they were designed to get the "subject" talking.

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SEXUAL HEALING:

by Beth Weinstein

OUR SEXUAL HISTORY

Sexuality is a huge issue for the haemophilia community. Before HIV was even a concern, we were warned about men passing on the gene for haemophilia to daughters; or, for the women who are carriers, giving birth to a haemophiliac son.

Many of us have been made to feel guilty for choosing to bear children. What effect does that have on our feelings of self worth, our desire to be sexual, and in negotiating intimate relationships?

Having a clotting disorder can also affect one's body image and consciousness as a sexual being. Joint damage, limited movement, and altered physical appearance play a role in how those with severe haemophilia see themselves and function sexually. For all of us in the haemophilia community, what are our feelings about our bodies? Do we have fears of acceptance by actual or potential sex partners?

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THE BIRCHGROVE WOODLAND PROJECT

In 1995 The Birchgrove Group will undertake with The Woodland Trust to create a living and lasting monument to all those haemophiliacs who were infected with the HIV virus. We feel that a grove of trees would be a fitting representation of our lives and a reminder of the continuing cycle of nature and its message of hope and renewal.

This major project will be concentrating on planting a grove of trees within a community forest as a permanent commemoration to all haemophiliacs who were infected with the HIV virus. This grove of trees is not intended simply as a memorial to those who have died but is also meant to demonstrate the resilience and strength of those

who are still affected. We are hoping to create a visible demonstration of the scale and significance of the tragedy that has affected the haemophilia community. The Woodland Trust has offered us an opportunity to plant this grove of trees in a new 100 acre community forest site, at Stratton near Swindon. The planting would begin in the autumn of 1995.

This joint project will be launched at our conference weekend in Manchester, on November 26th-27th 1994 which is the start of World AIDS Week. Funding permitting, we are hoping to complete the project during the summer of 1996. We know that this community forest will be a peaceful place for people to visit and remember all

those people who have had their lives affected by HIV.

As you can imagine, a project of this scale will eventually cost a considerable amount of money. We will be asking people to sponsor a tree to dedicate on behalf of someone who is living with or has been affected by haemophilia and HIV. Sponsorship of an individual tree will cost £25 and this will help to pay for the planting and ongoing care of the tree. If you sponsor a tree you will receive a Certificate of Sponsorship, which will give information about this woodland grove and record an individual's name. Further details about this exciting project will become available later in the year.

Many haemophiliacs and their partners have experienced the difficulties of coming to terms with HIV and the attached social stigma. I am not only referring to those who were infected with HIV but also to those haemophiliacs who were not affected. The truth is that all haemophiliacs were affected.

Initially, the government and the haemophilia community dealt with the catastrophe by seeing money as the easiest solution. The medical fraternity felt out of their depth, and offered their only hope - AZT. Our relationship with them became distant and there now seems to be a decline in HIV care at some Haemophilia Centres since AZT has been shown to be less effective.

Our relationship with the haemophilia community has also become more difficult and distant, some have projected their own fears onto those who were infected. I am waiting to meet a haemophiliac who will say, "I was lucky, I was not infected, but I want to come and help others who have been infected." In comparison, the gay community has helped each other, infected or not they have given care and support.

Yet, situations never remain static. There is a challenging theory I came across called "The Paradoxical Theory of Change", if there is a resistance to change, there must also be an energy resisting that. The "paradox" is that if energy is present, transformative change will come about. Like a dam, which holds back water, the energy needed just to contain the water is enormous. If released the flow can be turned into constructive energy. If let out all at once, the transformation will be dramatic and initially destructive, but nevertheless there will be a change.

What I see is our energies flowing with the Haemophilia Society, The Macfarlane Trust and the medical profession so that we can work together. People may feel that they have gone a long way to extend the hand of friendship and this relationship may not have been easy for them. But there is still much work needed to develop good human relationships with The Macfarlane Trust, the medical profession and the haemophilia community. We need to talk before it is too late.

by Rigo Fritz

An issue close to the hearts of a great many of us that frequently comes up when we talk amongst ourselves is dry skin eczema, the scourge of the HIV+ but well. And the longer we remain well in other ways, the worse that particular problem seems to get.

I have suffered from dry skin all my life, and from the eczema it causes in HIV for something like 4 years. My particular clinic did not seem to think it a problem at all. As the eczema concentrated on the usually "hidden" parts of the body - at times I was covered by these itchy patches from shoulder tips to ankles - and was more of a nuisance than anything else, their "specialists" nodded their heads, opened the drawers of their desks and started handing out what looked suspiciously like free samples. They started off with DAKTACORT. Useless. Then came CANESTEN, the "green" variety. Useless. Ahh, we do have something stronger CANESTEN, the blue variety. Just as useless as the other lot. When things got worse and I turned up on their doorstep almost every week, complaining bitterly about their incompetence in getting rid of something as "minor" as eczema, I was prescribed a canister of DIPROBASE. It did as much good as the other stuff, none at all, zero, zilch. By that time things were beginning to turn nasty and I was digging up the ghastly little patches of itchy miniature pimples by the nail-load.

Help came from an unexpected quarter, the USA. I have a friend in the States who sends me HIV related write-ups such as AIDS CLINICAL CARE and the like. I read them from cover to cover, although some of the medical jargon must makes even a professional reach for the dictionary. Still, one of the reports mentioned

zinc and its healing qualities for all sorts of skin complaints, with a particularly high success rate having been registered in HIV-positives who suffered from dry skin eczema.

After 8 years of living with the virus I have reached the stage where I would try almost anything to get rid of these nuisance complaints like thrush, eczema, fungal infections. I do it within the boundaries of my own common sense and reason, and I have not fared too badly, so far. I was most certainly willing to give zinc a try. Off I traipsed and got myself some zinc. Mind you, I didn't know there are different types of the stuff. So, I asked the sales assistant for help, and she recommended ZINC PICOLINATE, which contains Zinc (as picolinate) 22mg. I took a tablet a day, with breakfast, and I was totally eczema free within 3 weeks. That all happened about 2.5 months ago, and I have not had an itch since. Well, not of the scratchable type anyway...

I am not saying that everyone with a skin problem should rush out and get himself some zinc tablets. I am aware that one should not overdo the intake of zinc without balancing it out with copper. But your health adviser should be able to tell you what is best suited for your particular circumstances. So, do ask your GP, or your consultant or health adviser at the clinic whether it is OK to take zinc, which type and how much. There are ways of dealing with the minor problems we all encounter, although it seems that is best achieved by word of mouth rather than by putting too much trust in cash-strapped, money-pinching, no-longer-all-that-interested-in-HIV National Health Service Trust Hospitals, my very own personal opinion...

Extract of a letter from Body Positive Newsletter

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A WEEK IN THE LIFE OF A "SIAMESE TWIN"

by Gareth Lewis

The week begins after a restless Sunday night, with sleep being broken with worries about this, that and every thing else as well. It's 8.00am, you drag yourself out of bed, the children are their normal unruly selves and you start to think about the meeting with the Mac Trust in two hours time, is it worth it? Will they listen? Don't worry my 'Siamese twin' (the 'twin' is Paul Jenkins) will be there, he will give me help and support.

You look at the clock. It always takes longer to start on a Monday as sometimes you just might have been able to rest and forget about the Birchgrove Group for a few days, but coffee in hand, Mac Trust in seats and we are off. Why have you done that? Why can't you do this? Don't you think your trustees would agree to this? This goes on for many hours after the Trust have left, and so you begin to plan the trip to Manchester on the following day. Monday is not even over and we are already planning Tuesday, but it's really important that things are OK; as we are the people who are left to pay, but don't worry my 'Siamese twin' will be there, he will give me help and support. So it's back home to see the kids. You are tired, you are angry - it's been a long day.

Tuesday, and it's time to go. We have already been up to the office to check on this and that. Three hours later we arrive in Manchester at the hotel, after we have picked up an area rep who hopefully will show us the way, we sit for a few hours with a hotel manager. Can't you make it cheaper? Can we have this for nothing? And maybe you could throw in that as well? After knocking the cost of the hotel down, it's back to Warrington for a quick cup of coffee and make a phone call back to Cardiff. We think we have forgotten a meeting in two hours time, but don't worry my twin will be there; he will give me help and support. So three hours later, we arrive home totally worn out. A quick hello to the wife, and up to bed as Wednesday is fast approaching and we have a local Birchgrove steering group meeting to attend in the day and a Haemophilia Society meeting in the evening. All day Wednesday is taken up with planning and structural work for our local group, which all goes very well, with new faces, who will hopefully be taking on some of the day-to-

day running of the group to give us more time to concentrate on national work. We leave the office at about three and head home for a bite to eat and some well earned rest before it is off to town again, missing a rugby international at the Arms Park, for a local Haemophilia Society meeting. All goes well and then its home at 10.00pm and off to bed. By the way, my wife and children are still around giving me the help and support I need as I continue to fight against the elements of HIV & Aids. Now there's dedication for you!

Well, Thursday is here and it's up the the hospital by 9.15am and get to the office at about 11.45am. Spend the rest of the day working on various projects for Birchgrove and get home at about 4.00pm. This is a rare event I have the whole evening to spend with my wife and kids, but wait - the phone has started to ring and most of the evening is taken up with sorting out various internal representatives duties. End up getting to bed at about 11.45pm.

Ready for a 9.00am start, up the office we have two meetings planned for Friday, and I wonder how I'm going to cope, but don't worry my twin will be there, he will give me help and support. I'm at the office at 9.00am and start the day dealing with the phone and ringing back those who have left messages. We have a meeting at 11.00am with our local HIV coordinator, which is why we need to be on the ball. But we have a good working relationship with him and things go well.

I think we are ready for the next meeting of the day, which is to finalise the agenda for the conference and to work out where we are going to get the funding from to pay for it. Things get really heated at times, as the strain of the last week begin to take hold and the meeting goes on until nearly 5.00pm. We think we've got most things covered but who knows? Sit down to watch Paul Hooper on the TV and give him a ring to see how he feels after his TV role. It's late on Friday and where has the week gone? I think I'll ask my twin, but he is not there. I think the operation was a success and we have finally been separated until Monday when it all starts again, but don't worry my twin will be there; he will give me help and support.

THE BIRCHGROVE

offers a forum for discussion on:

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

THE BIRCHGROVE

believes that HIV positive persons:

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

CRYPTOSPORIDIOSIS...

The following are extracts from discussions on the InterNet, Sci Med. Aids items.

Cryptosporidiosis is an infectious disease caused by the parasite *cryptosporidium*. It is transmitted to humans by direct contact with an infected animal or by ingestion of food or water contaminated by faeces containing the parasite. The disease is characterised by a severe diarrhoea that is difficult to treat. Among individuals with advanced HIV disease, cryptosporidiosis may be life-threatening.

HELPI!

I recently experienced a horrible two weeks of the worse diarrhoea and vomiting ever. The stool sample came back twice saying that I had cryptosporidium. My doctor will not write me a prescription for medicine because he says that there is no treatment for crypto, and that it clears itself eventually. I disagree with him. People do take something for this, but I don't know what it is called. What drug can I use to definitely kill the crypto and make sure that it doesn't come back at a later time, like when my T cells are too low to fight it? Please suggest a brand name and dosage so that I can go back to the doctor and demand it. *Thank you.*

Hi,

To a certain extent, your doctor is right. cryptosporidiosis does resolve in people with intact immune systems!! that's not you, so your doctor is already misinformed. Second, while there are no definitive treatments, there are things you can try that work for some people. Various antibiotics have been tried with minimal effect (although more recent data should be reviewed). These include clarithromycin (Klacid), azithromycin (Zithromax) and spiramycin (ACTG 113). Atovaquone (mepron, 566c80) seems to work a little better. Humatin is another drug being investigated that has some benefit (also known as paromomycin). It seems to be fairly non-toxic and controls the diarrhoea. Aminosidine in a tiny study seemed to help control diarrhoea. Other approaches include eating bananas (as many you can); try sprinkling corob powder on some apple sauce. Octreotide may also provide some relief from the diarrhoea but does not eliminate the organisms. I hope you find this information useful—and that you find a treatment that helps alleviate this devastating diarrhoea. *Hope this helps.*

Hi..

In a Washington University School of Medicine study of people with AIDS and cryptosporidiosis, participants received paromomycin. All participants experienced a response to paromomycin characterised by decreased diarrhoea, stabilisation of body weight and/or eradication of the parasite from the stool. Several uncontrolled studies now suggest that paromomycin is a promising drug for the treatment of acute cryptosporidiosis. People with HIV infection who acquire this debilitating infection should discuss using paromomycin with their doctor. The drug is available by prescription, and its adverse side effects are generally manageable (nausea, abdominal cramps).

Hi,

I have been using colostrum to treat a case of diarrhoea which started April 23rd. I have a CD4 count of 7. We tried everything - no relief. I was beginning to think I would spend the rest of my life on immodium. Anyway I just went ahead and started using colostrum. The diarrhoea stopped within an hour like a charm. Then I stopped it - as I was unconvinced that it had helped all that much - so after another month of torture playing with immodium, metamucil et al - I went back to the colostrum. God, the stuff is a miracle drug for me - actually the Food and Drug Administration considers it food. Colostrum is a food. Colostrum is the secretion formed in a female's (human or animal) mammary glands before her baby is born. It is the most important food the newborn infant will ever get. It contains substances that provide temporary immunity against many diseases and afflictions until the baby's own immune systems starts to work. It contains substances that destroy viruses as well. The important thing to remember about colostrum is that it is not standard - it depends upon the cow you get it from and the history of infection. That is why they infect the cows with cryptosporidiosis. If the cow lives and has a calf - then the colostrum will have the appropriate antibodies. This is very exciting since as we could try to develop colostrum with various antibodies. Since mother nature has packaged these immunoglobulins in a form to resist digestion - we have a novel and exciting new delivery system for immunomodulation.

QUESTIONS...

by Anon

Dear Doctor, do you think I may, ask you a question or two, about some Factor 8 I took, in 1982?

You said it might cure my bleeds 'n aches, which it did in a sort of way, but it also gave me HIV, I'm very sorry to say.

So Doctor dear, though it wasn't clear, would it not have been better, to have written a letter, to tell me your obvious doubts? all the facts, as then known, relevant risks could have been shown!

Dear Doctor pray tell me, as a rational man, why not share your concerns, lets have no impropriety, when playing roulette of the Russian variety, with other people's lives?

These are just some suggestions, of the possible questions, as a Doctor you might well be asked.

In the last issue of The Birchgrove Newsletter we offered our thanks to the National AIDS Trust for their support, since that time most of the employees have resigned and left the organisation rapidly. In this issue we would like to thank the Haemophilia Society for their kind and continuing support, and wish them all the best in the future.

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The views expressed in each of the articles are those of the individual authors, and not necessarily those of the Birchgrove Group. The Birchgrove is a forum for discussion and seeks to encourage debate on the issues that affect haemophilia and HIV, the treatments of haemophilia and HIV, ways of staying healthy and how haemophilia and HIV affect love and sexuality.

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NO CHANGE...

Despite the tragedy of infected and impure blood products, it seems as if the lessons have not been learnt. We are concerned that the apparent purity of imported blood products may only be skin deep. Britain is still heavily dependent on imported blood products and it is essential that product safety is the primary concern. The following is an extract of a very challenging article that we believe should be discussed.

Corey S. Dubin

Earlier this year a man died in Ohio after receiving red blood cells. The red cells were contaminated with *Pseudomonas* bacteria which should not have been present in the Red Cross product. Meanwhile at the South Florida Blood Services a lab technician, in a letter to the Miami Herald, revealed an appalling situation. She described how on her own initiative she tested one hundred units of blood already labelled for shipment to area hospitals. She discovered that 7 units were contaminated, 4 with HIV and three with Hepatitis C. It is important to note here that before being labelled for shipment all blood is required to be tested for viral markers. According to this technician the blood she tested was imported from Europe and Latin America. This while the Red Cross continues to assert that they are not using imported blood.

Under growing pressure, they finally dispatched an inspector. His report contained some alarming conclusions. The most startling revelation was that for 5,000 units of blood with positive viral markers (indicating that these units were contaminated with virus) there were no final disposition records. Translated this means they did not know what happened to the 5,000 units of contaminated blood.

These discrepancies represent warning signals similar to those that were ignored during the early 1980's. Is history to repeat itself, or will we learn from our costly and tragic mistakes. As long as money is driving the decision making process and not absolute concern for safety it appears that we will have a repeat performance of the AIDS crisis from some yet unknown viral challenge to the blood supply.

We are also confronted with the issue of Parvo virus, which we know is currently present in blood and blood products. Yet no warnings have been given to those using blood and blood products. When queried about the need for warnings regarding the presence of Parvo, The Office of Blood Director Dr. Jay Epstein said "that since we do not know what the impact of Parvo is we are not prepared to order the manufacturers of blood products to include warnings on the product label". Yet in persons with Haemophilia whose immune systems are compromised we have seen numerous cases of Parvo related anaemia. This alone should be viewed as an important warning signal of possible serious problems ahead.

The current assurances of safety must be placed in the context of the events of the 1980's. Given that little has changed in the business of blood, pronouncements of the blood industry must be met with scepticism. Through continued vigilance and principled demands for safety we can attain the highest available standards. We must return concern for human beings and not profit to the decision making processes. This we must accomplish, the complete overhaul of the business of blood.

original copyright c. Corey Dubin May 1994 Sci Med Aids Item
From: Corey Dubin, coyoteradio@igc.apc.org, InterNet

PAUL'S PRESTIGIOUS PORTION...

by Paul Kimberley

Just who is right? Over the last few months I have kept a very close eye on various HIV periodicals. I now feel that a dilemma faces me and there seems to be no easy way around it. I have known my centre director for over 11 years now. During that time I have always found him to be helpful and informed, especially as haematology is his forte. However, it is because of this that I am particularly concerned.

Reading so many articles with information relating to recent developments in the HIV field, I have now tend to wonder how this information should relate to myself? I do not tolerate Septrin at all well, it makes me feel very sick, and I had been wondering about trying the desensitisation programme. Although I have no particular difficulties with nebulised pentamidine, my problems stem from other sources. I have been offered various pieces of information in this respect such as: - use 600 mg pentamidine per week, supplement with a bronchial dilator first, ensure the outlet pipe hangs through an open window, stand up, sit down, move around and stay still. No doubt I don't need to continue telling you all the permutations.

When I spoke to my centre director, he was quite satisfied. He suggested that I was well covered by my current regime. Whilst I have no intention of arguing with him, how on earth do I ignore what other people tell me? They are in exactly the same position, i.e., with nor prior PCP infection (*pneumocystis carinii pneumonia*, a common infection in HIV treated with drugs such as Septrin and nebulised pentamidine. editor). Why is it that the information we receive about the treatment of others, is in such contrast to the actual treatment which we are receiving? I know we are all different but surely that can't explain all the differences.

For several years, I have travelled monthly to the hospital for treatment, and then I was given a Medix Minor 3 unit to use at home. In the early days, I used to mix up the powder with the sterile water. Now of course, it's premixed, but again more bother. How often has your unit been checked? Who replaces the input and output filters? How often is it serviced? What about the droplet size? I confronted my centre director with this information and again received an answer stating that my unit was a good one.

The information about the droplet size did concern me. For what I was told sounded very logical. Too large and your tongue gets coated; too small and you breathe the droplets straight back out again. Let alone being told any information about not allowing someone else in the same room, without them having suitable protection, whilst you are nebulising. All very well informing me of this (in literature accompanying the pentamidine bottle) but what protection? In what size room? With which dose rate?

Perhaps some of you reading this through can appreciate my dilemma. If this is the case, I would like to hear how you deal with similar situations to that which I have described. When I have something more solid to work on, perhaps I can then take steps to deal with some of the varying information that we all seem to encounter. I would also like to hear from anyone who has found that the Septrin desensitisation programme does actually work.

You all take care now.



Treatment centres (and their staffs) have played a major part in the lives of many in our community. Although some professionals recognise that many community members are empowered consumers of health care, many have played a paternalistic role; or for nurse-coordinators and/or social workers (the greater percentage of whom are women), a maternalistic role. I've heard from many men that it is terribly embarrassing to have the women who provided care to them as children talk with them about their sexuality, especially since the advent of HIV. Many men tell me that they still feel as if they are children in the eyes of their treatment centre staff. And the underlying culture of paternalism which pervades many healthcare relationships (not just those related to haemophilia) can contribute to this.

In the early years of the HIV epidemic, there was intense denial about this disease in families, and among care providers. Prevention of sexual transmission was just not discussed very much. Certainly, whatever discussion did occur was mostly secretive. Unfortunately, much of the early risk reduction messages equated sex with death. "Use condoms every time or you'll kill your partner." It didn't help that a number of women were infected before anyone knew about risk reduction. Sadly, there are too many wives and partners who have already passed on.

I've heard stories from around the country about the risk reduction training offered through treatment centres. Some told about sensitive, confidential assistance. But some tales included counselling sessions in the clinic waiting room, or public hallways. Others talked about how the couples were split up and given divisive messages. There were many versions of the punitive message "do it right or die".

There were many family splitting and punitive messages offered, either overtly or covertly. One was that we shouldn't get pregnant, because we could die and kill our child as well. Another was that our men weren't keeping us safe enough, so it was up to us to make sure that we were responsible for safe sex, instead of communicating that it was a shared responsibility to be safe. Yes, there were significant moments of empowerment and fellowship. But the unspoken (and semi-spoken) messages formed a powerful undertow: Sex=Hiv, Hiv=Death; Therefore, Sex=Death.

INCEST AS A METAPHOR

It feels like we are in the process of incest recovery here, during the 1980s, the National Haemophilia Foundation (*in the USA. editor*) interacted with us in a very paternalistic way. In essence, they said to us, "Trust us, and give us your power. You can't know what's right for you unless we tell you. Don't worry, we'll take care of you, everything's all right." They were our daddy.

Unfortunately, the Haemophilia Foundation conducted itself more as a trade association than a consumer advocacy organisation. They exploited us by using the power that we gave them to further their own needs. Such as, building a strong financial base for their organisation by having the medical leadership focus on serving the interests of the factor VIII manufacturers, instead of focusing on protecting consumers from infection.

Another parallel dynamic is the conspiracy of silence that surrounds incest and our haemophilia-related HIV epidemic. During the early to mid-1980s, there were few organised attempts to even acknowledge the epidemic, let alone respond to it.

In 1988, Larkey, my partner, was featured in a cover story in our local paper here in Portland, Oregon. It told the story of how he became infected; it didn't even ask the questions of why, or who was responsible. Even so, we received death threats from members of our local haemophilia community, because they didn't want haemophilia to be associated in any way with HIV, even though their family members were infected.

Change is happening in a very powerful way, some of daddy's kids have grown up, taken their own power, and started their own families: like the Committee of Ten Thousand, and like Haemophilia Northwest.

Some of the kids have renounced daddy and have threatened him. Some are just now waking up to the abuse, they can hardly believe that their father would do those things to them; but their bodies and the documents don't lie. Others deny that Father could ever or would ever, abuse the family like the dangerous siblings say he did. The incest recovery metaphor is true on so many levels, including the historical context of the sexuality issues.

THE HEALING PROCESS

For many of us, it feels crucial that we get something from "daddy" around this "incest" process. We need him to listen to us in a very deep way, when we speak of our pain and anguish. We need him to validate the depths of our wounding, and to acknowledge that what happened was (and still is) very, very wrong. I'm not saying, that they should publicly admit wrongdoing, rather that they openly recognise the suffering in a way that allows us to feel seen, to feel heard; and to have this be done without defensiveness and denial. For those who still have a strong emotional connection to the Haemophilia Foundation, this validation and recognition would be a good beginning for the healing process.

Ultimately we need to heal ourselves as individuals and as a community; and not leave it up to "daddy" to make everything OK. One way to heal the community is through activism. You're reading it right now. Another way is to heal our own individual lives. Perhaps we can use our sexual healing as a metaphor for our whole beings. I am doing this now. And the synergy of working together will help the entire community.

It is necessary to learn many concepts in order to become a healthy, functional adult after surviving life threatening abuse when dealing with sexuality and/or health care. Some of these include, setting appropriate limits and boundaries around what each party is allowed to do, and/or is responsible to do; learning to insist on having full, informed consent to any acts and in making decisions; knowing the freedom to choose appropriate partners. I have struggled with many of these things for years in my own recovery, and know that it can take tremendous amounts of time and work to create healing. Please help our communities' health by creating open communication channels and to freely speak about what's important to any or all of us.

Beth Weinstein writes for The Common Factor, the US forum of The Committee of Ten Thousand which seeks to promote and advocate the needs of people with Haemophilia and HIV.

SPERM WASHING — The Media Encounter...

by Paul Hooper

When my partner and I decided that we wanted to start a family our main concern was, can you minimise the risks when you're up against the HIV virus? It wasn't a decision we arrived at overnight in fact it took us the best part of four and a half years to reach this point in time.

Our first enquiries took us both to my treatment centre as we thought that we would receive the most up to the minute information, counselling and support for couples in our situation. This, sadly, was not true. They couldn't tell us how many couples, whose partners are HIV positive haemophiliacs, had already had children. Considering that they are currently treating so many HIV positive haemophiliacs at my centre, why don't they have any figures?

Trying to make them listen to us wasn't working. In fact all they wanted to achieve before we both went home was to try and dissuade my partner from wanting a child altogether. One thing we did receive were two mercury thermometers for taking my partner's temperature but according to the nurse the ovulation charts aren't made any longer; so we would have to make our own. A few days later we discovered that if they had bothered to contact the maternity department (which is on the same site) the charts would have been ready and waiting for our next visit. Having looked to my treatment centre for support was a total disappointment. Thankfully we're not reliant on the treatment centre for all our medical advice, so we began to ask the same questions elsewhere.

Our GP pointed us in the direction of a "Well Woman Clinic" to try and find out what medical science could offer to a couple in our situation. Our first visit to the "Well Woman Clinic" was so different from

our visit to the treatment centre. We were actually treated as sane individuals who were aware of the risks involved in wanting to have children when you are HIV positive. We went on to discuss in more detail the options that are available to us. After counselling sessions, open and frank discussions and non-judgmental consultations, samples of blood and sperm were taken. We needed to know exactly how fertile we were if we were going to conceive using the "Rhythm Method". This means having unprotected sex once a month, at the time of ovulation.

Throughout all of this, we are now receiving what we feel to be the best possible advice. Although we had to seek hard to find it after approaching my own treatment centre and failing to get anywhere, this does not mean that all treatment centres are the same. Thankfully some people have access to treatment centres that try harder to understand and meet individual needs.

Mark Weaving, the Press Officer of the Haemophilia Society was approached by the BBC because they wanted to interview a couple who were trying to start a family, though one of them was HIV positive. They wanted an item for Tomorrow's World about Doctor Semprini in Milan, Italy, who is offering couples in our situation "sperm washing" to make the risks involved as small as possible. Mark Weaving contacted the Birchgrove Group, some of whom knew that my partner and I wanted to start a family and they know and understand only too well what this means to us.

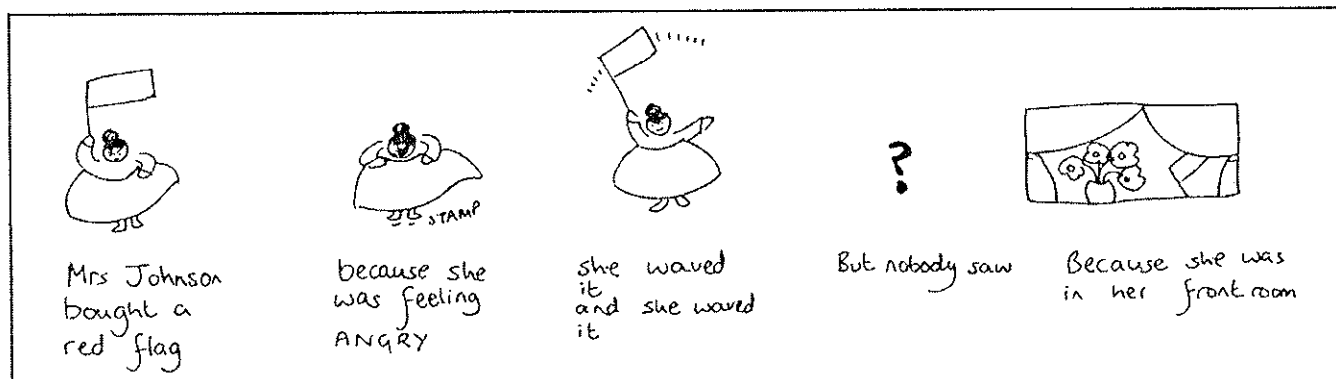
A decision was needed quickly, so I sat down with a large sheet of paper to list all the positive and negative aspects of being interviewed, and the positive far outweighed the negative. Several phone calls later I met Chris Wells who was researching and producing the story. He

made it clear that he would give me as much anonymity as I wanted. We discussed at length what it was like being HIV positive, the stresses and strains that this has caused in our relationship, and our hopes to have a child.

A date was set for the filming, which was to take place near where I live. The evening before was spent with all sorts of thoughts whizzing about in my head. Had I really made the right decision? What if someone recognises the back of my head? (*I'd recognise the back of your head anywhere. editor*) Needless to say it was just a case of nerves and nothing else. When I arrived at the location my stomach felt as though it was tied up in knots and I was starting to panic. But these feelings soon ebbed away when I met Shanaz Pacraban, the programme's presenter, Martin the cameraman and Brian the sound engineer. Shanaz put me at my ease almost straight away so that I was able to relax and forget about the filming and concentrate on the interview.

Although I only have limited knowledge about the technique that is being offered in Milan, I knew that before you can be accepted for sperm washing you must have several tests carried out in your own country and then send the results to Dr. Semprini. He will examine the results and decide whether you are suitable for the procedure. Some doctors feel that what Dr. Semprini is doing is not totally acceptable, and that he is encouraging people to who should be dissuaded from taking these risks. I personally feel that Dr. Semprini is offering a chance for couples who are trying to fight the HIV virus to conceive in the safest possible way using the technology that is available at the moment.

If you would like further details about the sperm washing technique please contact the Birchgrove P.O. Box. editor



THE PAS INTERVIEW... continued

Never let it be said that I can't talk when required. Where do I get my support? "Well usually from family and friends", What needs did you have? "I need good clear information". What sort of information? "Well, despite having the virus for so many years I still have unanswered questions that worry me" "Like what?" "Well, when I die what will my widow have to deal with? I don't even know whether they still put your body in a black bag and seal it up!" At this my interviewer burst out laughing! I still don't know whether she was acutely uncomfortable or whether she thought that I meant a black plastic refuse sack. As I began to get steadily more unhappy during the interview. I felt a need to reassure myself of her abilities.

Having put myself in the Mastermind chair with the spotlight, I needed to know that my interrogator was up to the job. "Will you have to travel back to London?" I asked "Oh no, I only live locally," She said. This

was a bit of shock! I assumed that being a London based research company that its interviewers would be based in London and that would give some additional confidentiality to the situation or at least it might mean you wouldn't have to bump into the interviewer in the street.

I was getting increasingly uncomfortable about this woman's background, had she been a social worker? had she worked as a counsellor or in a caring profession? "I've not met anyone like you before", she said, "but I'm very broad minded."

"So who do you work for when your not doing research for PAS?" "Well, I do product research for all sorts of people, sometimes I have to be the mystery shopper and ask the assistants for awkward things, sometimes I do market research in the street, oh I've done all sorts of research." "What was your last bit of research?" I asked, and that was the big one, "I was working for Persil!" she said.

BODY POSITIVE NORTHWEST

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A MANUAL FOR LIVING WITH HIV...

At the Madrid World Gathering of People with HIV/AIDS in 1990, the Innovation Project showed how people living with HIV rarely had access to the information they feel they need when they feel they need it.

Surveys of opinion have confirmed this. The idea of a self care manual was conceived. It would be:

- an introduction to all the areas of interest and concern to a person living with HIV
- easy to refer to and dip into
- diverse since people with HIV have diverse needs
- able to be understood by those without specialist knowledge

- jargon free
- accessible to those not in touch with support groups

The West Midlands Regional Health Authority has produced a regional manual. The manual contains much that is universal and also local regional information. The aim of the manual is to enable people living with HIV to have relevant information to hand if, and when they need it and to know where to go if they need further information and help.

It provides:

- a clear and concise guide to enable people to feel empowered to make choices that are appropriate for them

from a position of knowledge

- a tool to identify the unique programme that they decide is right for them
- information in a form which allows the user to pick and choose

The manuals concept is that there are no definitive answers and many choices for people living with HIV. The manual is an aid to negotiating what is right for you; your feelings are always held to be valid. Each individual is held to be unique, what the virus means to you; what you choose to do; how it will work out and the ability to move along a scale of information.

Further information is available from the Birchgrove Group PO Box.

Please send me copies of the quarterly Birchgrove Newsletter directly. Please send me information about the Birchgrove Group.

Please send me information about Birchgrove Woodland Project.

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