



Birchgrove

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the sex issue...

Sexuality should be a huge concern for the haemophilia community. Even before the advent of HIV, we were counselled about the risks of men passing on the gene for haemophilia to their daughters; or, for women who are carriers, giving birth to a son who was a haemophiliac.

Establishing a relationship and starting a family has always been a loaded issue. Accepting the realities of a genetic condition which not only affects the sufferer but can also affect the children is a responsibility which we have always been made to face. Many of us have consequently been made to feel guilty even about deciding to have children.

What effects have these pressures had on our feelings of self worth, our desire to be sexual, and in the establishment of intimate relationships? Having haemophilia also affects one's body image and therefore one's consciousness as a sexual being. Joint damage, limited movement, and altered physical appearance all play a significant role in how people with severe haemophilia see themselves and how they function sexually. For all of us with haemophilia what are our attitudes about our bodies? Do we have fears of acceptance by actual or potential sex partners?

Facing up to being infected with HIV and being infectious has served to reinforce an already negative self-image. Sex and sexuality are issues that many people with haemophilia are reluctant to examine, subjects that we are all too quick to push back into the closet.

Haemophilia centres have always played a major part in the lives of haemophiliacs and their families. Although some professionals recognise that many haemophiliacs can be empowered consumers of health care, many have played a very paternalistic role; or for nurses and/or social

workers, a great percentage of whom are women, a maternalistic role. Many haemophiliacs say that it is terribly embarrassing to have the women who provided their haemophilia care to them as children, then trying to talk with them about their sexuality. This has become especially significant since the advent of HIV. Many haemophiliacs say that they still feel as if they are children in the eyes of the haemophilia centre staff. The underlying culture of paternalism which pervades many doctor - patient relationships (not just those related to haemophilia) often contributes to this atmosphere.

In the early years of the HIV epidemic, there was intense denial about this disease both in families, and amongst the medical care providers. Prevention of sexual transmission was just not discussed very openly. Certainly, whatever discussion did occur was shrouded with embarrassment and secrecy. 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 already infected before anyone knew about risk reduction. Sadly, there are too many wives and partners who have already died.

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WARNING • WARNING • WARNING

This newsletter contains sexually explicit language. We hope that many of the articles are offensive or at the very least positively smutty. We believe that the repeated use of rude words will help to broaden peoples vocabulary and may even broaden their minds!

Sex, drugs and rock 'n roll are issues that are very close to the heart of the Birchgrove. So it will come as no surprise that we have chosen to cover these important themes in our forthcoming issues. (Any comments or contributions are always gratefully received.) This issue we are taking the opportunity to re-examine the concerns surrounding sex and sexuality.

Some of you may remember in the dim and distant past that our medical professionals made two simultaneous decisions. They not only decided to tell us that we were infected with HIV but they also took the opportunity to (perhaps for the first time) discuss our sex lives and/or our sexual proclivities. This double shock was not easy to come to terms with.

At least not many of us have had to bother with any more of those irritating little "safe sex" talks or any more of those intimate "counselling sessions" with embarrassed professionals who seem more awkward about what we get up to in bed than most of us did. I suspect that this embarrassment factor has made SEX a subject that most haemophilia centres no longer feel eager to tackle. But we are still HIV positive and we still have sex.

Where is the safe sex literature? Where is the support for our partners? Where is the support for people who are establishing new relationships? It is an increasing concern that many who at one time practiced strict "safe-sex" procedures no longer feel the same sense of urgency. Do you still wear a safety-belt? There are some who never bothered to start!

This surprising lack of energy and effort going into information for people who are positive cannot help the rest of the community. There are many anecdotal examples of positive men who are not willing to take on the responsibilities of being HIV positive. It is perhaps a little ironic that the health promotion authorities put such efforts into persuading people who may not be positive to "take care" and little or nothing into those people who are a guaranteed risk to the rest of society.

What about a safe sex campaign for those living with the virus? Not, "this is how to avoid AIDS" but "this is how to face another bloody condom after ten years!". What about risk reduction for those who have become sick and tired with the whole concept of HIV, "safe sex for the terminally bored."

SAFE SEX - WITH A COW!

Phobias have made the national headlines in Zimbabwe and in the United States. In Zimbabwe, Israel Zinbange was convicted for having sexual relations with his cow. His defence was based on nosmaphobia, which in this case includes the fear of contracting HIV from a human sexual partner.

In a similar story from Washington DC, uniformed CIA officers wore latex gloves when a delegation of lesbian and gay officials attended a meeting at the White House. While nosmaphobia may have been a factor in this action, other psychiatric terms describing the Secret Service's behaviour include homophobia, auto-mysophobia, katagelophobia, and spermophobia.

At least, the Zimbabweans' HIV/AIDS education programs are effective. Zimbabweans understand how HIV disease is transmitted, which is more than can be said for US federal employees. Israel Zinbange was sentenced to jail as a consequence of his nosmaphobia. The Secret Service officers will probably only be ordered to attend a hastily constructed and useless HIV seminar. Justice might be better served if they were sent to work on a Zimbabwean cattle ranch for a few months.

The next issue of the "Birchgrove" newsletter will be on the theme of Drugs. We would be pleased to publish peoples views and experiences both of using prescribed medicines and recreational drugs such as marijuana, ecstasy and alcohol etc.

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 people with haemophilia and HIV. We would encourage anyone who may have strong views regarding any of the items published in this newsletter to write to the Editor. We are keen to publish any thoughts or views which help promote a healthy debate. No assumptions should be made regarding the health status of any individual whose name appears in this publication.

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

The family splitting and punishing messages offered, either overtly or covertly, were responsible for adding insult to injury. One message 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. The unspoken (and semi-spoken) messages formed a powerful undertow:

Sex=HIV, HIV=Death; Therefore, Sex=Death.

I sometimes feel that we are in the process of incest recovery here. Many health care professionals have chosen to treat us in a very paternalistic manner. In essence, they have said to us, "Believe in us, and give us your trust. You can't know what's best for you unless we tell you. Don't worry, we'll take care of you, and everything will be all right." They were our daddy.

Unfortunately, a dependence on this paternalistic health-care system has not helped us to deal with a disease that was injected into us by the doctors who said they had our best interests at heart. We need to realise that decisions were and are often made on financial grounds rather than purely medical grounds. We need to see our health care as part of a larger economic and political picture. Not simply a relationship between an injured child and a caring parent.

During the early to mid-1980s, there were few organised attempts to even acknowledge the epidemic, let alone respond to it. The medical world had difficulty in confronting the realities of the situation. How could the freeze dried concentrates that they recommended be contaminated? How could best practice be so wrong?

An analogy can be drawn between the silence that surrounds our haemophilia-related HIV epidemic and silence that surrounds incest. Some haemophiliacs are only now waking up to this abuse. They can hardly believe that their "father" would have done those things to them, but the effects of HIV on their bodies is evidence that does not lie. Others deny that this "father" could

ever or would ever, abuse the family like these dangerous siblings say he did.

But for many of us, it feels crucial that we get something from "daddy" around this "incest" process. We need to be listened to in a very deep way. We need to speak of our pain and anguish. We need the depths of our hurt validated, and to have acknowledged that what happened to us was, and still is, very, very wrong. Perhaps we need to hear someone say that they are sorry.

I'm not saying that they should publicly admit wrongdoing, but that they should openly recognise our suffering in a way that allows us to feel seen and to feel heard. That this should be done without defensiveness and denial. For those of us who still have a strong emotional connection to the medical profession, this validation and recognition would be a good beginning for a healing process.

Ultimately we need to heal ourselves as individuals, and not leave it up to "daddy" to make everything OK. One way to begin the healing process is through activism. This process can help us demonstrate that we are children no longer. You're reading it right now.

Another way is to try and heal our own individual lives. It is necessary to learn new concepts in order to become a healthy and functional adult after surviving life threatening abuse when dealing with sexuality and/or health care. Some of these things include; setting appropriate limits and boundaries around what each party is allowed to do, and/or is responsible for. Learning to insist on having full, informed consent to any procedures or any decisions, and being aware of the freedom to choose the appropriate people to support and advise us.

I have struggled with many of these things for years, and I know that it can take tremendous amounts of energy and courage to become responsible for one's own healing. Each individual's contribution to this fight for independence can help the health of the haemophilia community. We must strive to create better communication channels between health care professionals and patients and we must learn to speak openly about what is important to any, or all of us.

This article is based on ideas of Beth Weinstein who writes for The Common Factor, the US forum of The Committee of Ten Thousand.

Remember when fucking was fun? Remember when just about anything went? When the exploration of each others' bodies meant both the giving and receiving of pleasure, and was an expression of love? When you didn't have to worry about STD's because there were drugs to sort them out?

Those were halcyon days, the Days Before Condoms (DBC). It all ended for me in the Summer of 1985, when I was diagnosed as being HIV positive. I was informed by Centre Director, a man who, though not lacking in empathy, seemed acutely uncomfortable with what he had to tell me. It took quite a while for all the ramifications of the diagnosis to sink in - hardly surprising given the conflicting information I received on each separate visit to the hospital.

The first visit it was, "Don't worry too much because only 10% of HIV positive haemophiliacs go on to develop full blown AIDS," but by the second visit it had risen to 50%. Shortly after the message was, "You'd better make a will, son, because 90% of you will be dead within three years."

There was however, one constant: "Don't, whatever you do, have sex." Just to complicate matters further, at the time of the diagnosis, my wife was five months pregnant. Of course she was offered really helpful advice like, did she want a termination? Given that she hadn't contracted the virus, and that this might be our only chance for a child, we politely told them what they could do with their termination. On second thoughts, perhaps we weren't so polite after all.

This great big "No" of sex lasted throughout the Summer and on into Winter. My daughter was born in November of that year and I was becoming somewhat demented from this prolonged spell of unwanted celibacy. The rationale as it was explained to us was, "You just can't take the risk of infecting your wife and child; condoms aren't reliable; just abstain till we think of something; what did God give you hands for, anyway?" My wife gave birth by a Caesarean section, which meant that our period of abstinence was further prolonged, till we were finally informed by the centre Social Worker, that there was some light at the end of the tunnel.

This light was called "Safe Sex." Suddenly condoms were okay; not only were they okay, they were cool, they were hip, they were sexy. Suddenly, every bastard seemed to be wearing them, they became a fashion accessory. They

were even advertising the damn things on TV. The thing was that I could still remember the DBC. And while condoms might look cool hanging out the arse-pocket of faded Levi 501's, given the choice, I think most HIV positive people would rather not have to use them. Most of the good looking, healthy actors used to sell the condom concept, actually had a choice - they weren't infected with the virus. If you're given a choice about something - anything - then you're free to experiment; if something is imposed on you, then it becomes a drag.

But in those days, just being allowed to fuck again was a joy. As long as you could bury the fear and worry of infecting your partner through some accident with a condom. As long as you could cope with sex that was gentle to the point of passivity; as long as the missionary position was all you needed to get by.

But what if these things weren't enough? What if you weren't happy to consult a checklist each time you jumped into the sack with your partner? A checklist that said, "Don't come in (or on!) your partner; don't stick your tongues down each others' throats; don't bite, scratch, lick or suck; don't get carried away; don't stick it anywhere other than where nature intended; and don't do oral sex."

Picture the scene, the lights are turned down low, the two of you are kissing and cuddling, feeling yourselves getting aroused, the juices starting to flow. Clothes are abandoned, limbs get tangled up, you're thinking about only one thing, when that internal alarm goes off. Uh-Oh. Out comes the mental checklist; you run down it, asking can we do this? No. That? No. How about this then? Yes, but only when the moon is in Scorpio, and only then if it's a leap year and the month has an "O" in it. Jeez, I can hardly wait!

I guess this is about something that was stolen from me, and not just from me, but from my wife. Call it the innocent pleasure of sex, for want of a better term. The freedom to enjoy sex without having to worry that I might kill my wife as a result of my sexual drives. This is a major part of my life that's been limited; not only has my immune system been compromised, so has my sexuality. I miss all the things I can't do, and sometimes I feel bitter and angry. I resent the fact that we can't take the risk of unprotected sex to try and have another child. This issue, has perhaps, been the bitterest pill to swallow.

And yet somehow, we've adapted; we've adapted because we've had to. The first thing we did was to give up on the safe sex manuals and

rely on common sense. Then we started experimenting with different types of condoms. There are so many on the market now, you can feel bewildered by the choice. But trying all the varieties can add to the fun. You can get your plain, run of the mill type Johnny; Superfine for extra sensitivity; ribbed; coloured; flavoured - try Lemon and Lime, that's a favourite of ours - extra-strong for the paranoid, extra large for the liars; you can even get Johnnies that glow in the dark!

And then of course there's foreplay, which, with a bit of imagination and experimentation, can often be the most exciting part of love making. We've discovered that foreplay isn't necessarily merely a prelude to penetrative sex. In fact, the pleasure that can be derived from touching, stroking, caressing and licking, can lead to an orgasm as intense and as satisfying as the orgasm from actual intercourse. The only limit is the imagination, and as my wife keeps telling me, "sex is as much in your mind as it is in your genitals".

Honesty is crucial to any good relationship and especially when it comes to sex. But if one of you is HIV positive then it becomes absolutely essential to work out how you discuss things between the sheets. If all the issues aren't discussed, then fear and ignorance can create an insurmountable barrier to a full and happy sex life.

But, if both partners are fully aware of the issues, are honest with each other, open about what they want from their sexual relationship, and they both give their consent, then there are numerous ways in which they can give each other pleasure with minimal risk.

In regaining control of our sex life, we have found the confidence to take control of other aspects in our lives. HIV and AIDS has ceased to be the defining characteristic of who, and what we are. I have been forced to become more intensely aware of sexual issues in our relationship and I have had to develop the confidence to take responsibility for those decisions that effect the health of me and my wife.

The most important thing to me is no longer the state of my HIV or which new prophylactic drug to take, (the only prophylactic that I'm interested in these days is the kind that you wear on your dick!). But watching our daughter grow up, my wife's career, finishing my degree, friends, holidays, a glass of red wine and a good movie.

HAND JOBS

The Canadian AIDS Society Guidelines state that there is a "theoretical risk only" (this is a category lower in risk than "low risk") of infection to the person receiving mutual masturbation of the vagina or penis because semen or vaginal fluids may be present on the partner's hand. These fluids may get into the bloodstream through a cut or perhaps directly through the mucosal lining of the urethra or vaginal opening if semen or vaginal fluids are used as a lubricant. However, there is no empirical evidence of HIV transmission by this route. There is "no risk" if a water based lubricant is used instead of semen or vaginal fluids.

Usually, there is "no risk" of transmission to the partner giving the mutual masturbation. Risk can be increased to "theoretical risk" if there are cuts or sores on the hand and there are vaginal fluids or semen that can come into contact with those sores. Again, no documented risk of infection has ever been demonstrated for this activity. Using latex or polyurethane gloves for this activity decreases the risk but is also considered "theoretical risk only" since there is always the possibility of tears or rips in the glove.

Most of my reading has cautiously presented the fact that there is some risk of communicating HIV (and probably some other organisms) if there are breaks in the skin of either partner. For instance, a bad hangnail or cuts on the hand of the stroker could provide an avenue for infection if contact is made with semen, blood or vaginal fluids of the strokee. If the strokee has sores on the penis or in the vagina, the sores can provide both a source of infection for the partner and a means of infecting the person with the sores. On the other hand (no pun intended, but take it for what it's worth), my partner is HIV-negative after more than 10 years of giving me great hand jobs.

(The editorial board would like make it clear that despite an endless amount of regular experimentation it does not seem to be possible to re-infect yourself through masturbation!)

BY MARK WEISNER, PH.D.

Passion? What passion? It's only a faint glimmer on a far off horizon. You've been with the same partner forever, and you wonder what happened. The romance, the intrigue, the innuendo, those nights of racing over to meet each other, the passionate kisses, the sex... gone. You stand in the bathroom and wonder if it's worth the trouble to even get something started.

Once you've ruled out physical or emotional causes, and if you have had a relatively problem-free sexual appetite in the past, try some of the following suggestions:

Arrange intimate times together. Sexual play can start with innuendo in the morning for activity in the evening. A lot of sexual pleasure is created by anticipation. A midday phone call, flowers sent to the office, a love note expressing your eagerness to be together - all increase your sexual energy level.

Make "sex dates," stop waiting for spontaneity. The reality is that people who are newly sexual usually "plan" having sex. As they dress for the evening, and plan their time, they allow for, and even arrange situations for sexual contact. Do you remember the days when you changed the sheets on the bed because you knew you'd be having sex?

Think about activities that lead to sex. You can arrange to have sex now, just as you did back then. Perhaps a romantic prelude is in order...a quiet dinner for two, or a walk on the beach. Having a large meal before sex can take the fun out of it. Think ahead.

Use your imagination. Fantasise freely. If you are bold, share your fantasies with your partner, either before going to bed or during love making. Ask directly for what you want, either in a note or in person. Experiment and watch your desire grow.

Make a list of sexual preferences in the form of a menu. Include appetisers (foreplay), main course (intercourse or acts leading to orgasm) and dessert (afterplay). Exchange filled-out menus with your partner. Completing a sexual menu makes it easier to communicate verbally with your partner later.

Experiment. Plan something new with your partner every now and then. Carry it through even if it makes you a little uncomfortable. This will increase your repertoire and appetite.

Play with one another. Have sexual play leading to orgasm without intercourse. Learn to focus on other aspects of intimacy - using all five senses.

Practice touching each other differently. Ask what kinds of touching, and where your partner prefers to be touched. Slower, faster, lighter, harder, more to the right, more to the left - these are the kinds of directions that can be helpful.

Be generous. If you are receiving directions, don't expect that tomorrow your partner will want the exact same kind of stimulation. Just as people change from day to day in their intensity of orgasm, it is quite normal to be more or less sensitive from one day to the next. Gently ask for directions if you aren't getting the kind of response you expect.

Notice your reactions. Focus on your own feelings and share them with your partner, so you won't lose the focus of your own body. If you are both concentrating on what you are "doing to" the other, your efforts will cancel each other out. Focus on what creates positive sensations for you. Tell your partner exactly what to do to make it increase.

Do some research together. Sit down together and leaf through a sexual manual that presents different sexual activities and positions. Sharing this input becomes a catalyst for discussion. If you can communicate sexually, you will be able to communicate on any level.

Be flexible. Orgasms are not mandatory; the goal of making love is mutual pleasure. Whatever gives you pleasure is enough. If one of you is not well or too tired for an orgasm, stop. If being held is your idea of pleasure, ask for it. If your partner insists that you give him or her an orgasm, and you don't feel up to it, ask them to take care of themselves. If you keep turning your partner down, take the time to look at the problem seriously.

Get the big picture. Understand that what happens in your relationship is a generally reflected in the bedroom. If your partner avoids having heart-to-heart talks with you in the relationship; you might find yourself feeling a lack of his/her presence during lovemaking. You might end up feeling like you just had sex when you wanted to make love. Talk about the difference and see what happens.

Get help. If you can't make these suggestions work, seek out a therapist who works with sexual issues. Most sex therapy only requires a few sessions if you don't have a problem history. Having a rich sexual life is healthy, and worth the effort it takes to create.

Author Mark Weisner, Ph.D. is a Psychologist and a trained sex therapist, lecturer and author.

Sperm washing today

The first article on this subject was published back in November 1994, firstly in this newsletter and subsequently in the Haemophilia Society's Bulletin. Out of the blue the Macfarlane Trust stopped funding any forms of fertility treatment from November 1994. I still haven't been able to get a clear answer, why they decided to stop funding for all forms of fertility treatment.

Sperm washing in the UK has developed to the point where at least four hospitals are now asking for HIV positive men to give samples of semen, so that the sperm washing process can be tried and perfected. Thus, in the very near future, they should be able to offer sperm washing to couples so that they can start a family with the minimum amount of risk.

The technique itself isn't anything new, it's used regularly in IVF treatment. It's just that they have to make sure that they are using the right technique and that the results are the same each time. Getting this far has taken almost two years, so when are they going to be able to offer this to people who are HIV positive? I'm being told this could take as long as late 1996 or perhaps even the middle of 1997 before it becomes available.

Why doesn't someone fly Dr Semprini into the UK and let him spend some time with the Doctors here, so that the process can move along more swiftly for everyone concerned. In Italy to date there are now 99 children who are here thanks to Dr Semprini's efforts and the first child is now six years old, perfectly well, and going to school.

If someone here had taken a leaf out of Dr Semprini's book, perhaps my partner and I would have been saved so much heartache and desperation in trying for a baby. Its almost a year since we started having unprotected sex once a month to try and have a child.

Some people have said that in offering this technique that they would be making widows with orphaned children. This is such a load of rubbish, I'm tired of reading such negative crap. Who can say just how long anyone might live? Events happen that are totally out of anyone's control. I could go out one morning and be killed by a chunk of frozen piss that's fallen from a 747 on route to the Costa del Sol.

Couples have baby's all the time, so what makes any other couple more secure from death than us? All I want is to be able to father a child as safely as possible. To do all the things that any father wants to do, read bedtime stories, play in the park, see our child grow, watch their first steps and hear their first words. Is that really too much to ask?

CYBERS

What is Cyber Sex? Something which separates one from the "real thing" from actual physical contact with another. Simulated sex, where the real disappears and is continually replaced by a physical simulation.

A prothesis one could say.... better known as a rubber, a johnny, a condom or a whole piece of virtuous reality (if used). One is touching without touching, and one is intimate, most intimate. At a distance of only a millimetre or kilometre. Concealing the interface between image and imagination. Surfing on the retinal skin.

The word cyber, pertains to a substitute that stands in for the "real thing", for the human element. If there is a "real thing". As a piece of virtu-reality, it refers to a realm of phantasy, electro-erotic encounters of the third kind; electric dreams of electric sheep, encountering your ideal.

In electronica, the sphere where phantasies are realised to be absent. Where the fantastic is generated to deliberate the body. Where everything is freedom in an enforced restriction. Where the orgasm is endlessly deferred, differing endlessly, the pleasures of cyber sex.

A prosthetic realm where everything is possible, an electronic image which has more erotic potential than linear pornography. An enlightenment that seizes the viscera and tightens the entrails to reveal an emptiness. A space where sex is always delayed.

Safer, yet the risks are endless. Always the erotics of the electronic screen; the prophylaxis between you and the other; that is the erotics of cyberspace; cybersex... safersex.

Dear Sir

John Lauritsen's thought provoking article "The AIDS Hypothesis" in Issue no. 6. raised many interesting and contentious issues surrounding the role of HIV in Acquired Immunodeficiency Syndrome or AIDS. This controversy involves questions fundamental to the general theory of diseases being caused by the invasion of malign organisms: bacterial, viral, fungal etc. Many of these problems are of a technical and scientific nature, but underlying them are problems which are semantic or conceptual in origin. The complex nature of these problems make them hard to sort out especially, as Lauritsen pointed out, as they are often couched in technical jargon. Lauritsen in his article makes three definitive claims:

1. That there is no such thing as AIDS
2. That HIV is not harmful
3. That people said to be suffering from AIDS become sick not from AIDS but because they lead unhealthy lives or take dangerous substances.

Let us examine the first claim: "There is no such thing as AIDS." Indeed it is true that people diagnosed as having AIDS do not suffer and die from any single disease entity. Acquired Immuno-deficiency Syndrome or AIDS is by definition a 'syndrome': which means a collection of symptoms not necessarily related to a single cause or agent. Their symptoms and death result from the invasion of a variety of disease organisms: various pneumonias (viral/bacterial), candida (fungal), Kaposi's sarcoma (cancer) etc. While such diseases do exist in the general population not infected by AIDS, they are extremely rare, and prior to the advent of AIDS in the early eighties, such diseases were not often seen in succession, as is often the case with HIV infected patients. In haemophiliacs there were almost no reported cases of deaths from such diseases, prior to the early eighties.

An analogous situation can be seen with cancer. If it is the case that AIDS is not a real construct, because it has a variety of causes and symptoms, so we would have to say cancer does not exist either. The cluster of diseases known as 'cancer' also has many forms and a variety of causes. The common link being that cancers are all the result of unrestricted cell growth, this unrestricted growth is in turn linked to the failure of certain genes to regulate cell division. It is this common linkage which defines the construct known as cancer.

eventual breakdown of the auto-immune defence system of the body, because of the destruction of the T4 and other cells involved in the defence against invading organisms and cancerous cells, which allows opportunistic pathogens to invade and cause disease. The link in all these cases is the presence of HIV.

The second contention is that "HIV is not harmful." It is true that the virus itself does not directly cause the diseases which frequently attack those diagnosed as having AIDS. It is not a direct cause of disease, but an agent which undermines and weakens the body allowing in other disease causing organisms, or undermining the normal development of the body's cells. This is true of other viruses and bacteria: the herpes virus, for example, is always present in the body but only manifests itself in cold sores etc. when the body is weakened by stress etc.

So what is the cause of such diseases? Is it the virus, or is it the weakened condition of the body? In the case of cancer, is the cause the carcinogenic substances, the unrestricted cell growth or the faulty gene? It is like the case of a person who is shot - what is the cause of their death? Is it the gun or the bullet? In the case of AIDS, what can be said is that the presence of all these factors: the weakening of the immune system by the virus (HIV), and the invasion of secondary pathogens seem to be necessary conditions.

Let us examine the third contention: "People said to be suffering from AIDS become sick not from AIDS but because they lead unhealthy lives or take dangerous substances." It is obviously true that leading a healthy fulfilled lifestyle can greatly improve your chances of resisting disease and mental illness. If you do not smoke or drink alcohol to excess you are far less likely to suffer from cancer of the lung, heart disease or liver malfunction. Likewise a healthy diet, and possibly vitamin and mineral supplements, can help protect us from a variety of ailments, including, according to Lauritsen et al, AIDS.

However, is this the case with HIV infection? People who have avoided drugs (including those currently used to treat HIV/AIDS), and followed healthy diets etc. have still gone on to develop those conditions commonly associated with AIDS. While many others who have taken those drugs currently used to treat HIV infection and inhibit the onset of AIDS have not. If all that is necessary to avoid AIDS is to avoid drugs and follow a healthy lifestyle, then anyone following such a regime should not develop AIDS symptoms, but

this is plainly not the case.

As far as iatrogenic diseases are concerned, in the case of haemophiliacs HIV infection, along with various hepatitis viruses, are indeed iatrogenic infections (that is caused by medical treatment), but what would have been the consequence of not taking treatment? Most older haemophiliacs know the answer to that question - severe and painful disablement, and probable death, from continuous severe haemorrhages.

Obviously it is better, all things being equal, not to ingest any 'drugs', even aspirin or paracetamol, however we all take them to control pain etc. as a means to avoid greater problems. In the same way many take low doses of AZT, and other substances, in order to facilitate further research into HIV treatment, or as lesser evils in the hope that they will inhibit the virus. Powerful drugs like AZT certainly involve risk, but they are given in extremely low dosage and monitored for side effects. Of course in the current state of knowledge there is no certainty of success, but if we know there is something out there trying to kill us, is it not better to take some precautions, however uncertain?

David Edwards

Dear Sir

I was pleased to read the "AIDS Hypothesis" article in issue 6, and I welcome the fact that Birchgrove is encouraging its membership and readership to understand the hidden truth about how people who are given a "HIV antibody positive" diagnosis really are (mis)-treated by the drug centred approach of so-called medical experts.

The article was a vivid reminder of my own experiences with Septrin, Dapsone, AZT and Pentamidine - these "treatments" made my life hell. I was made very ill while on AZT, Septrin gave me a violent allergic reaction, and Dapsone put me in hospital - something HIV (whatever that is...) never did. The last time I allowed my consultant to monitor my CD4 count in 1993, it was falling from around 560 down to 350 after exposure to Septrin and AZT.

Good health for me has depended on avoiding toxic medical drugs ever since. It's been about listening to others, and remembering that "cures", "vaccines" or "effective treatments" for the ever-growing number of conditions they call AIDS are not available from Medical Departments (or any medical practitioners for that matter).

the aids debate - letters

What is available from these "experts" concerns many people. Prominent people such as Peter Duesberg have spoken out - regardless of the trend of current popular opinion to support and encourage drug treatments and trials - against AZT, a deadly drug which is still being prescribed today.

In the news we learn that in spite of over enthusiastic articles by Edward King (NAM) and in spite of over prescription by doctors (a cheap drug is a good drug!), Co-Trimoxazole (Septrin, Bactrim) is now to be restricted in its use (but probably not for "AIDS" patients...) due to the severe reactions it causes some people, and the potentially lethal side effects which affect most people who take it.

No-one has yet provided a convincing argument to explain why, if someone has apparently unconnected symptoms - few of which have anything to do with immune deficiency and a diagnosis of the presence of antibodies to an indeterminate virus called HIV means that they then have a syndrome called "AIDS". Even worse, no-one has proved that HIV, if it exists, would necessarily cause any disease which would justify the use of a discredited and previously outlawed anti-cancer drug such as AZT, or the related experimental drugs such as ddi, ddc or 3TC, or anti-immune drugs such as Thalidomide, all of which are capable of destroying the human immune system. And I most certainly don't want a baboon's bone marrow anywhere near me!

From my point of view, my consultant has let me down. I am scared, but not powerless. I continue to ignore medical "opinion" - not everyone with AIDS consumes quantities of drugs. My local "drop-in centres" - namely the supermarket and the pub - continue to provide me with the well-being and the hope which I need to survive and not to be alienated by the HIV/AIDS industry. Keep the debate alive!

Garry Davies

Dear Sir

I found issue N° 6 of the Birchgrove both interesting and challenging. Your opening article "The AIDS Hypothesis" is an unequivocal endorsement of the challenge to HIV hypothesis. The logical conclusions from it for your members would be to throw away your condoms as there is no problem from spreading HIV, and you were given the "compensation money" for HIV acquisition from contaminated treatment under false pretexts as it is a harmless organism. I personally

consider that these are dangerous and unjust messages to perpetuate.

I contrast this article with the anonymous letter on page 10. The couple writing in are clearly offended by the alternative explanation offered for "AIDS", from the HIV is irrelevant hypothesis, namely that "symptoms are self-induced by over indulgence in alcohol or nicotine, or a mid-life crisis". In my opinion this is the weakest part of the challenge to HIV hypothesis, as it does not explain all the findings, blames the individual for their own health problems, and pushes back the notion of guilt and innocence.

The author of the article falls into the same trap as those he criticises, namely that of strongly pushing one opinion - instead of balancing the pros and cons. There are possible negative consequences of following the beliefs of alternative theory, and these should be acknowledged.

AIDS, by definition, is not a single disease entity which is why the word syndrome is used. The only common link found so far between people with that diagnosis is the presence of HIV, but that does not make it causative of ill-health. I quite agree that people whose HIV is inactive, may be coincidentally developing the indicator diseases, and in many ways the term AIDS is becoming as unhelpful as the term ARC was. Active or inactive HIV disease may be more useful terms, as it makes clearer whether the virus is playing a part in someone's current health problems.

It is good that people with haemophilia are taking increasing control over their health care, and your newsletter is helpful in that. The fierce independence I found working with the men involved in haemophilia, was the most exciting aspect of the work.

Shirley Mallon

Dear Sir,

I do not support the hypothesis that AIDS does not exist or that HIV is inactive - my own personal experience shows this not to be true. But, I do think the article raised many important issues. As a haemophiliac I have developed a deep cynicism for medical opinion. I have had a lifetime of being put in plaster casts, forced to wear callipers and advised to take hot baths and jelly to stop the bleeding. All these pale into insignificance when I recall the medical opinion that said "don't stop taking factor 8 just because it's not heat treated, risks from bleeding are far more dangerous than any risk of AIDS!"

What about when we were offered high dose AZT because that was the best medical advice or when we were offered Septrin without any discussions about side-effects. The best medical advice and the best drug regimes have in the case of haemophiliacs given us all a kaleidoscope of potentially lethal viruses. We are a classic example of people made ill by their medicine.

Some of the messages in the AIDS Hypothesis article to re-assess the values of current drug treatments, to focus on reducing the health risk elements in life, including alcohol and cigarettes and to seek the support of a good advisor, are of enormous value. As an experienced patient, I believe that one of the most health promoting activities is to take responsibility for your own well-being. To make active personal decisions about medical and alternative treatments and only bother with them if they honestly seem to be doing you any good.

I think it is time that we began to share our burden of haemophilia and HIV, not just with our centre directors but with health advisers who might be able to give us a balanced view.

Paul Jenkins

Dear Sir,

I don't think I've ever read such rubbish in my life. Of the more than 1200 haemophiliacs who were infected, over 700 are now dead. How did they die? Did they simply imagine they were ill? Did they imagine their T-cell counts were falling and that all sorts of strange things were happening to their bodies? It wasn't my imagination that I suddenly started wearing condoms!

It doesn't matter what you call HIV or AIDS, the facts are simple: 700 dead haemophiliacs is surely proof enough that they were infected with something that killed them. To deny the existence of the illness is absolute stupidity. Where will it all end? Will they be telling us that there is no such thing as haemophilia? That we are simply imagining that our blood won't clot? Such denials are stupid and insulting!

Anyone who has witnessed the suffering and death from AIDS of a friend, who prior to diagnosis, was fit and healthy will surely have no sympathy with these views. It would be better for everyone if the writer of the "AIDS Hypothesis" channelled his energies into finding a cure and helping people infected with this horrendous disease, instead of denying its existence.

Alan Burgess

It used to perplex me, then I thought what's the point just get on with things, they are that way and you can't change them, probably a standard thought for a positive haemophiliac. Only this one happens to be gay as well. Somehow it seemed to fit in with the pattern of having been lumbered with everything else, except being gay does not come secretly freeze dried in a bottle.

In the early years, I used to think that I must be the only guy with haemophilia who was positive and gay - what a combination! It often presented me with problems that some days seemed insurmountable. What if I did not have haemophilia, would I still be positive?, a question that subsequently I did get asked on many occasions. Of course no-one can answer it, not even me, but it does raise a very interesting issue. If I went along to a Body Positive type group meeting all went well until I mentioned that I had haemophilia. For some reason the people there felt that my HIV was different to theirs! I had also thought about ringing the Haemophilia Society, but as they were unprepared to accept that those of us with HIV even existed, trying to explain about being gay felt even more difficult. I would have had more success getting through to a phone on the moon.

So either way I had no clear access route, it was a case of either keep quiet about being gay or don't mention the haemophilia. So for several years this was just what I did.

But there came a point in time when I was no longer prepared to hide behind the facade of these situations. I decided that the very first person to get told would be my centre director, and that I would gauge from his reaction if I had got the approach right, and hope that he would not be the last person that I would want to tell. It was at the usual check up appointment, after I had received my mandatory examination that I told him. I don't know why, but when he just answered yes, I think I was more taken aback than him, he was just so OK about it.

I suppose having known him for over twelve years, he had probably worked it out for himself anyway! But that initial step of actually telling him made such a difference, that I wished I had told him many years before. That attitude of instant acceptance made me realise that it was time to set the record straight elsewhere and over the next few months I made a point of not hiding behind the familiar partial explanations. Since then my life has changed considerably, and for the better. Fear of the unknown is hard to ignore

and so is prejudice, but I just didn't want to spend any more time in the shade rather than in the sun.

I have since joined my local haemophilia group, which is one of the most successful in the country, with many events being attended by over 200 people. I was invited to join the committee and found that they all took to me instantly. Which made me realise even more just how wrong you can be about people, and that works both ways.

It has also opened boxes that had previously been very securely locked, particularly when my self-esteem had gone into decline. However, since being open and honest, I must admit the effect in many areas of my life has been quite dramatic. There does seem currently a growing acceptance of gay people and the realisation that we really are no different to anyone else. After all, the gay community really has got its act together (and has done so for many years now) particularly, when it come to support in the field of HIV and AIDS.

For me, I feel distinctly proud of not only being gay, but having the guts to not hide my sexuality. You see what's on the outside so often reflects what's really going on inside. Just look at peoples' faces when they have indigestion!

This also leads me onto another area, sex. Now, I'm certainly not going to tell you everything about what I get up to. But I will tell you that I'm very careful about myself and towards other people. Sex, particularly the safe variety, is a somewhat vexatious subject due to the primitive way that the human species replicates itself. However, I do feel that there is a considerable amount of misconception (sorry), about what gay guys get up to when they're alone together.

Now, I'm not going to give you any intimate sex lessons here, but we do all love our partners just the same as you married guys do. I personally am proud of being in a relationship for 16 years. It's not always been easy, but we have come through. We have faced the future together, planned and now there is a sealed brown envelope and that's it. I have spent more than enough time at best pondering, at worst, worrying about the future and what it may hold. If you can get decisions like that behind you, it makes the road so much straighter and clearer.

And what has all this got to do with sex you might ask? Well, behind you and straight a head, need I say more?

Early in June 1985, I received a letter from my centre director asking me to call down for a chat at my convenience. So my partner and I turned up at the centre and she was asked if she wouldn't mind waiting while I saw the doctor. By this time I am beginning to wonder what the fuck was going on? My mind was working overtime. Then he hits me with the news that I've got something called HIV, but "not to worry as it probably won't affect you as you're fairly young and healthy."

I ask all the usual questions; Am I going to die? Can I still have children? What about my partner? We're supposed to be getting married in eight weeks time, what am I going to tell her for fuck's sake? He then speaks the immortal line that I will never forget, "You don't have to tell her if you don't want to." After what seemed an eternity she was asked to come into the room and I try to tell her what I've just been told. We cry a bit, and after a brief "don't worry" from the doctor we're ushered out into the corridor where we stand for at least ten minutes in total confusion.

Anyway, we somehow managed to get through the next few weeks, and lo and behold, she still wanted to marry me. The wedding day came, and all went well. A quick shag in the afternoon and back to the reception. Got totally bollocksed at the evening reception (good for my Hep C!) then headed back to our love palace for a night of unbridled lust. Well we went at it like there was no tomorrow, upside down, inside out, back to front every which way you can. Then I decided that I needed a drink, so I got up and switched the light on.

There was blood all over the place, our bedroom looked like something out of a scene from *Nightmare on Elm Street*. My wife was covered in blood, the room was covered in blood and I had blood all over me! Unknown to me my foreskin had snapped during one of our athletic sessions. Panic set in, I couldn't stop my dick from bleeding. What to do now? All I could think of was, get in the bath and try and wash off some of the blood. So there I was, two o'clock in the morning, sat in the bath trying to stem the flow of the blood from my throbbing genitalia.

Several bottles of factor eight and a few days in bed soon mended my wound, but the mental scars took much longer to heal. Looking back it was probably one of the most worrying times of my life. For Christ's sake, we weren't even using condoms in the early days.

PLASTIC CONDOMS

Safe sex has met the space age: You can now use condoms made of plastic! Why would you want to use plastic condoms, you ask? Here are a few reasons:

- Plastic condoms can be made much thinner than latex condoms. Since they are thinner, some men think they feel better. Three out of four men who have used the new plastic condom said they felt good.

- Plastic condoms have a looser fit. Some men like condoms that aren't as tight-fitting as latex condoms. They say looser condoms feel better.

- Plastic is a very strong material, so plastic condoms may not rip or tear as easily as latex condoms. Many couples complain that latex condoms tear when they try to put them on, or that they break during sex.

- Plastic condoms can stand up to oil-based lubricants. Couples use oil-based lubricants like vegetable oil, mineral oil, massage oil, or even saliva to make the condom slide on. These oils make latex condoms weak, and they break more easily.

- Plastic condoms can be kept longer without breaking down in heat or cold. Latex breaks down if it has been exposed to heat or cold too long.

- Plastic condoms also get weak if they have been in a wallet for too long.

- People allergic or sensitive to latex can use plastic condoms. Some people get a rash if their skin touches latex.

Because they are new, scientists don't know as much about plastic condoms as they do about latex condoms but tests have been done in their labs; and they show that sperm or infectious germs can pass through the plastic material. Currently plastic condoms cost more than their latex counterparts.

One thing is for sure: the condom you can buy is called plastic. Other companies are working on plastic condoms for men, so you should have more choices soon.

ORAL SEX THE CASE FOR...

This is a hotly debated topic. Certainly the claim that oral sex is as risky as intercourse can be refuted. Even the most conservative researchers agree that the risk is far lower than anal or vaginal intercourse.

The debate centres around the degree of risk for oral sex, specifically what level of risk is acceptable, as contact with semen or seminal fluid in the mouth will never be 100% risk-free. The points of view range from minuscule risk if ejaculating is avoided, to a low, but still unacceptable risk. The research can be interpreted to fit one's own view on the topic, since there have been only a handful of documented cases of oral transmission, usually involving ejaculation, and often with mouth sores or ulcers present.

In addition, there is the reporting problem: people are ashamed to admit that they had unsafe intercourse, and have been found to admit only to oral sex initially, and then later admit to unsafe intercourse. This clouds the data.

What seems clear is this: for a man to get a blow job is most likely extremely safe, as is a woman receiving cunnilingus. Whatever risk there is comes from giving head, whether to a man or a woman. For now, individuals need to make a personal decision regarding the level of risk they choose to take.

This fits in with a harm reduction model: substituting a low-risk activity, oral sex without ejaculation, for a high risk activity, anal or vaginal sex without a condom, may assist people in staying safe over a period of many years. Eliminating all these activities may make long-term safe behaviour more difficult.

One literature review states:

- the presence of infectious virus in the oral cavity is an uncommon event;
- PCR data indicate that HIV sequences may be present in the oral cavity at reasonably high frequency—further studies are warranted;
- saliva appears to contain potent anti-HIV activity that may be responsible for the low oral virus titre; and
- oral secretions are a reliable source for monitoring anti-HIV antibodies.

One study claims the inhibition of HIV by saliva is due to saliva aggregating HIV. Interestingly, there is little inhibition of HSV and no effect on adenovirus, so there is apparently some viral specificity. Ref: Malamud et al, Human submandibular saliva aggregates HIV.

I have innumerable friends who are in relationships with HIV+ men, and they have unprotected oral sex, but use condoms for intercourse. NONE of them has gotten infected. I test them, so I'm not kidding. If YOU are uncomfortable with it DON'T do it! But, some people know there is a little risk involved and are willing to accept that risk.

Everyday we take risks in our lives. When we drive to work, plug in an appliance, or any other of a number of things, our risk of getting killed in an accident, electrocuted, etc. IS REAL...and we accept that risk. Why is it that with HIV people think things are SO black and white. That the only acceptable risk is 0%. Nothing else in life has those odds. The truth is oral sex is much less risky than unprotected intercourse.

ORAL SEX THE CASE AGAINST...

The case against oral sex is not very hard to make. I realise that many people do not like to hear the facts, but the findings are out there if you want to look.

The rate of infection is not known precisely, but estimates have been made. It is important to remember we actually have no way of knowing what the rates of HIV sexual transmission are anyway. No one can conduct controlled studies or even verify what people do sexually since most of this occurs in private. All one can rely on are self-reports - so in terms of methodology the vaginal and anal transmission rates are no more reliable than the oral reports. All of which is confounded by the fact that many people participate in more than one type of sexual act.

A recent popular report states, "There are now dozens of such studies of people infected from oral sex, including gay men, lesbians, and heterosexuals, all of whom maintain that they were infected through oral sex." Dr. Alan R. Lifson, says, "Collectively, these reports now strongly suggest that HIV infection can occur in receptive oral intercourse, particularly with ejaculation but also without ejaculation."

In a recent random telephone poll of 24 top New York AIDS doctors, 19 said they had patients whom the doctors believed had been infected orally. Dr. Robert V. Gale said the evidence is convincing because of its cumulative nature. "I see it in my practice all the time," he says, "men without other risk factors, who claim they never had anal sex in their lives. I see it in significant numbers." Dr. Bernard Bihari who has been seeing AIDS patients for more than a decade can cite the precise details of the sexual

histories of deceased patients who he is convinced were victims of oral infection.

As Dr. Jeffrey Laurence, AmFAR's Senior scientific consultant for programs and a researcher in this field says, "In a large, well-controlled study done by prominent epidemiologists, oral sex has been demonstrated to be a definite risk. Based on solid epidemiological data, we can no longer say it's possibly safe."

Many used to think that HIV was difficult to get orally on the basis of monkey experiments conducted by the Centres of Disease Control in which live virus was rubbed into monkey's gums with no resulting infection. Jeffrey Laurence reports, "But now we've discovered that the inhibitors in saliva that block HIV are at much, much higher levels in monkeys." So much higher, he says, that the animal studies cannot reliably be applied to humans.

What about acidity or alkalinity of the mouth and gastrointestinal tract, including the stomach? As Harvard's Allison Quale, the lead author on the Harvard study, says, of course stomach acid will ultimately destroy the virus, but she compares that to closing the barn door after the horses are gone. "You'd probably be infected long before any HIV even reached the stomach," she says. "The way you're going to be infected orally is thorough the mucosa."

And of course we saw reports more than two years ago that breaks in the mucosal lining are not necessary to spread HIV - rectally or orally. As Quale, an immunologist and expert on mucosal defenses, points out there is a special mucosal immune system made up of various immune cells. "They have long arms that stretch out and pick up antigens such as HIV and pull them into the body." Dendritic cells do not kill their viral prey but bring them back to the lymph nodes. So, no skin breaks are necessary. Additionally as Anderson pointed out macrophages and T-cells also sit on or just beneath the epithelium of the oral mucosa and both types are highly susceptible to HIV infection.

I have no idea what the actual rate of transmission is, but people I talk to say about 1 in 200. Sorry you devotees of oral sex - it's just a matter of time before the actual rate is determined. In the mean time you take your chances.

SCREW YOU?

Why should anyone have sex with a positive haemophilic? There could, of course, be a lot of different answers to a question like that. But speaking for myself I think that I was caught rather unawares.

There I was, happily married and planning a family (hopefully three children), coming off the pill - I never liked those revolting condom things - when out of the blue, the most horrific bombshell hit us. My husband was diagnosed as HIV positive.

I can tell you, it can really turn you off sex for a long time getting told that the person your married to is HIV positive. Initially we were told to abstain from sex, which to be honest, came as quite a relief to me. I don't think that sex could ever have the same spontaneity again.

I was in a loving relationship, a relationship to which I was already committed. But HIV had not been part of the bargain. Although I chose to spend my life with a haemophilic, fully aware of what this might mean for his health in the long term, I didn't choose to spend my life with someone who was HIV positive.

I'll never be sure whether I would have freely chosen someone like him, in my heart of hearts I don't think I would. I think that self-preservation, the longing for children, and a "normal" sex life, would have made me retreat from a relationship with someone who was positive, before I became too deeply involved. But who knows?

I have spoken to other women, who although they are fully aware of all the ramifications, they have still freely chosen HIV positive haemophiliacs as partners. Is their love for their partners stronger than their fears about HIV? Are they willing to take the risk of unprotected sex in order to start a family? Maybe they don't want children. Perhaps, it's because they've been given a choice and that makes them less angry than me.

Despite my anger, and a sense of being cheated, I now have a beautiful ten year old daughter and a husband who is still alive and kicking. And what about sex? Yes... but please don't forget the condoms!

"How Jersey Senate Clears Bill Easing HIV Suits Against Pharmaceutical" Knight-Ridder/Tribune Business News (06/23/95); Shaw, Donna

The New Jersey State Senate has unanimously approved a bill that would provide HIV-infected haemophiliacs with one extra year to sue pharmaceutical manufacturers for products which infected them with the virus. An opinion from the state Attorney General's office says that the "subsequent legislation cannot revive causes of actions previously barred by a statute of limitations." However in a separate report, the Assembly's non-partisan Office of Legislative Services argues that even though the bill would pass on "dubious grounds," it may be unconstitutional as "special legislation" for AIDS-infected haemophiliacs. Gov. Whitman's spokesperson, Rita Manzo, says that the governor will review the bill, but she expects the Attorney General's opinion to have "a great impact" on the governor's decision.

"Removal of Blood Supplies Urged" New York Times (06/23/95) P. A18; Leary, Warren E.

An advisory panel to the U.S. Food and Drug Administration (FDA) has recommended that the agency recall blood products taken from donors infected with a rare neurological disease called Creutzfeldt-Jakob syndrome. Although the panel said there is no evidence that the fatal degenerative disease of the central nervous system is transmitted by the transfusion of blood, the group urged the FDA to withdraw affected supplies to maintain confidence in the nation's blood system. The panel was convened to advise the FDA on what to do about blood and plasma products discovered to contain blood from donors subsequently found to have the disease. Creutzfeldt-Jakob syndrome has been confirmed in seven donors over the last 12 years. After hearing testimony from haemophiliacs and other patients who said that any risk was too high, the panel unanimously voted to recommend that the blood from people with the disease not be used. The patients said that they did not have confidence in any scientific judgment that minimised risks in light of the many people who became infected with HIV via contaminated blood during the 1970s.

"A 'Topper' Movie in the Age of AIDS" New York Times (06/23/95) P. C16; Holden, Stephen

"Heaven's a Drag" is a movie that is determined to find inspirational uplift in the AIDS epidemic. While alternating between warty drawing-room comedy and tear-drenched pathos, the film also offers politically pointed vignettes on haemophilia and gay-bashing. The two principal characters are Simon and Mark, who live together in London in a sexually open arrangement. Mark is HIV positive. The film deals matter-of-factly with his illness, and becomes a profound exploration of unequal love between partners, repressed grief, and the legacy of Simon's bitter relationship with his late father.

"Germany Passes Pension for Victims of HIV-Blood" Reuters (06/29/95)

Germany's Parliament has approved the creation of a \$180 million pension fund for nearly 2,000 people who became infected with HIV from unscreened blood during the early 1980s and their dependents. The action was prompted in 1993 when it was revealed that, in order to save money, firms had failed to screen blood donors properly and check blood supplies for HIV for nearly 10 years. The primary recipients of the fund are haemophiliacs who were dependent on regular doses of blood plasma and were mostly infected before the HIV testing of blood products became requisite in 1985. People who contracted HIV from blood products before 1988 will receive a monthly payment of \$1,000, and those who have developed full-blown AIDS will be paid \$2,160 each month. The relatives of those people who have already died of AIDS will receive \$720 each month until they are 25, or if they are adults for five years.

"Clinton Assails Helms' AIDS Stance" Washington Post (07/06/95) P. A6; Devroy, Ann; Brown, David

On Wednesday, President Clinton asked Republican congressional leaders to ignore the issue of how people become infected with HIV, and focus instead on reauthorising a multi-million-dollar federal program that helps treat the disease. In letters to Senate Majority Leader Robert I. Dole (R-Kan.) and House Speaker Newt Gingrich (R-Ga.), Clinton urged approval of the Ryan White CARE Act, which was named for a young Indiana haemophiliac who died of AIDS. Helms, a vigorous opponent of gay rights, said in comments published in Wednesday's New York Times that AIDS funding should be reduced because homosexuals contract the disease through their "deliberate, disgusting, revolting conduct." Some Democrats and gay rights advocates responded with outrage to the comments. Rep. Barney Frank (D-Mass.), for example, blasted Helms as "a bigoted fool" and expressed concern that Republican leaders appear to be stalling reauthorization of the act, which expires in September. Clinton described Helms' contention that AIDS patients receive more federal funding than those with other illnesses as "a false argument." Total spending for AIDS research, treatment, and other funding in fiscal 1995 was nearly \$6 billion, while spending for cancer and heart disease totalled \$17.5 billion and \$38 billion, respectively. Related Story: Washington Times (07/06) P. A8

"Renegade" Doctors Saved Haemophiliacs" Toronto Globe and Mail (07/12/95) P. E7

White doctors and Red Cross officials in Canada embraced a new blood clotting product called Factor 8, two "renegade" doctors

claim they acted on instinct to save haemophiliacs in Alberta from becoming infected with HIV. Man-Chiu Poon and Andrew Keegi testified at a hearing on Tuesday into Canada's blood supply that they had doubts about its safety. They said they kept many of their patients on cryoprecipitate—a clotting product that is made from the blood of just one donor, while thousands contribute to the production of Factor 8. Keegi said he began to have doubts about Factor 8, which in the early 1980s was thought to be safe from the blood of American donors, after hearing that some U.S. blood banks were located in dangerous areas. Thus far, about 400 Canadian haemophiliacs have died from receiving the contaminated blood.

"Doctors Examine Weight Loss Caused by AIDS Virus" Reuters (07/12/95)

Researchers trying to discover why HIV-infected persons often lose weight concluded in a report to be published in this week's New England Journal of Medicine that the weight loss does not occur because HIV increases the body's metabolism. Instead, the virus appears to slow the human engine. HIV apparently causes its hosts to eat less or to use the food less effectively, they said. "Reduced energy intake, not elevated energy expenditure, is the prime determinant of weight loss in HIV-associated wasting," said the research team, led by Derek MacLellan of St. George's Hospital Medical School in London.

"Red Cross Issues Another Recall of Blood Products" Toronto Globe and Mail (07/19/95) P. A3; Abbate, Guy

The Canadian Red Cross Society has ordered the recall of additional blood products after learning that a donor has been diagnosed with possible Creutzfeldt-Jacob disease. This second withdrawal in two weeks comes after the agency discovered that the man had donated blood in August 1994. The only other time he donated blood was in 1985. Dr. Moung Aye, national director of blood services with the Canadian Red Cross, said that both recalls were precautionary moves and that there is no scientific data that show the disease is transmitted among humans via blood transfusions. Creutzfeldt-Jacob disease is very rare, with just one case per 1 million people diagnosed each year. It is thought to be caused by an infectious protein or virus. Recently, a physician testifying at an investigation into Canada's blood system cautioned that Creutzfeldt-Jacob disease could be the next AIDS-like epidemic.

"Safe Blood Units Refused, Documents Show" Toronto Globe and Mail (07/24/95) P. A3; Picard, Andrea

The Canadian Red Cross was offered a heat-treated blood product for haemophiliacs in late 1983, but refused it because it cost pennies more per unit, say documents filed at a public inquiry. The agency rejected the product again in early 1984, 18 months before it was made available to haemophiliacs in Canada. In the meantime, officials at the Red Cross played down the benefits of the safer concentrate. One senior official even ordered a supplier not to include a warning that the concentrate that was not heat-treated could carry HIV. The Commission of Inquiry on the Blood System is investigating the events which left more than 1,000 people infected with HIV and thousands more with hepatitis C. Consumer groups, including the Canadian Haemophilia Society, claim that although the disaster was not completely preventable, systemic inaction on the part of the Red Cross and other officials significantly exacerbated the extent of inaction.

"Across the USA: West Virginia" USA Today (07/25/95) P. 6A

Tim Snodgrass has been fired for refusing to deliver mail to a couple with AIDS. The postal worker was suspended last month after withholding Fred and Pat Grounds' mail. Snodgrass said he was afraid of cutting himself on the metal mail slot and becoming infected with HIV from handling envelopes and stamps the Grounds might have licked. Related Story: New York Times (07/25) P. A10

"A Lesson in Blood" New York Times (08/07/95) P. A13; Herbert, Bob

Although there were strong indications in the early 1980s that the nation's blood supply was contaminated with HIV, relatively little action was taken, writes Bob Herbert in the New York Times. According to a recently released report from the Institute of Medicine of the National Academy of Sciences, one of the reasons for this inaction was the belief of top blood products officials that moving too fast might prove expensive. The report said that the Food and Drug Administration was too dependent on the counsel of the industry it was charged with regulating. Now, critics of Sen. Bob Dole's (R-Kan.) regulatory reform bill are concerned that it is an industry-sponsored attempt to damage the agencies responsible for safeguarding Americans' health. The bill should have been dead, writes Herbert, but two senators—Charles Robb (D-Va.) and Kent Conrad (D-R.D.)—have tried to find a compromise to save the measure that was developed and largely drafted by members of the industry. This could be explained by the fact that Sen. Robb's former law firm, Hutton & Williams, helped draft the bill, which would be advantageous to its corporate clients, notes Herbert. In addition, Sen. Conrad has received nearly \$400,000 from PAC's related to the two industry groups, Project Relief and the Alliance for Reasonable Regulation. All in all, concluded Herbert, money should not represent the quality of our lives.

"Compensate AIDS-Stricken Haemophiliacs" Philadelphia Inquirer (08/05/95) P. A9; Klein, Andrew R.

Advocates of AIDS programs should thank Sen. Jesse Helms (R-

N.C.) for bringing attention to the dangerous status of the Ryan White CARE Act, writes associate professor Andrew R. Klein of Stanford University's Cumberland School of Law in the Philadelphia Inquirer. Another worthy, though much less-publicized, bill is the Ricky Ray Haemophilia Relief Fund Act of 1995, which is named for a Florida teenager who died of AIDS three years ago. The measure represents Congress' first attempt to address the plight of haemophiliacs who contracted HIV from blood clotting products. The bill, however, does not do enough; Congress should reimburse claimants for all medical expenses related to their HIV infection, Klein contends. In addition, pharmaceutical companies that produced blood products should be taxed to help finance the compensation fund, rather than use general funds. Although it is not yet perfect, the Ricky Ray bill is an ideal beginning to solving a terrible problem, concludes Klein.

"Two Charged After AIDS Deaths" Financial Times (08/10/95) P. 2

Prosecutors in Germany have charged two company officials with three cases of murder and 5,837 cases of attempted murder for distributing blood plasma which had not been screened for HIV. The prosecutors claim that nine batches of untested blood from an HIV-infected donor were sent to several clinics in 1986 and 1987, just after it became mandatory to test blood for HIV. The two men—the managing director of blood processor Haemophiles and the co-owner of a laboratory in Wollath—are also said to have delivered more than 5,800 shipments of frozen blood products throughout Germany, even though at least 84 percent of it had not been tested for the virus that causes AIDS. Related Story: New York Times (08/10) P. A7

"Senate Gets Bill to Assist Haemophiliacs with AIDS" Philadelphia Inquirer (08/12/95) P. A2; Shaw, Donna

A measure that would create a \$1 billion fund for haemophiliacs who became infected with HIV from tainted blood-clotting medicines was introduced to the U.S. Senate on Friday. The Ricky Ray Haemophilia Relief Fund Act, which is named for a Florida teenager who died of AIDS in 1992 after using a contaminated blood-clotting product, would award \$125,000 to each of the approximately 10,000 U.S. haemophiliacs who were infected with HIV in the late 1970s and early 1980s. A similar version of the bill was introduced to the House in February, and has thus far gained the bipartisan support of at least 110 members, sources say. According to the bill, the U.S. government "failed to fulfil its responsibility to properly regulate the blood-products industry" by not sooner requiring the use of available technology to purify the blood-clotting drugs.

"Possibly Tainted Blood Products Face FDA Recall" Philadelphia Inquirer (08/12/95) P. A2; Shaw, Donna

The U.S. Food and Drug Administration (FDA) is advising the recall of any blood products that may be tainted with the rare Creutzfeldt-Jacob disease (CJD). There is no test for CJD, an incurable, neurodegenerative disease that leads to dementia and death. Although the blood-products industry had cautioned that such recalls could lead to shortages of plasma-based medicines, the FDA said that if shortages occur, the products could be released with warning labels. In addition, the federal agency overruled its Blood Products Advisory Committee on the issue of whether a new HIV test should be used by blood and plasma collection centres once it receives government approval. The new test is expected to reduce the 27-day "windows"—the period between infection with HIV and the time it takes to be identified—by about six days. The committee had decided that the test would be too costly to justify the five or 10 lives it might save each year. The announcements are the latest in a series of changes made by the FDA, which was criticised last month in a report by the Institute of Medicine for being too dependent on the blood industry.

"Preventing AIDS: Have We Lost Our Way?" Lancet (07/29/95) Vol. 346, No. 8970, P. 262; Lison, Alan R.

Although the best way to curb AIDS is by preventing the transmission of HIV, millions of people already test positive for the virus, notes Alan R. Lison in the British medical journal The Lancet. Prospective studies have demonstrated that years can pass between HIV infection and the emergence of related infections and disorders. Two findings, however, now challenge the theory that HIV resides for years in a quiescent phase. The first is that active viral replication occurs in the lymphoid system well before significant replication is evident in the peripheral circulation. The second finding is that HIV replication occurs continuously in vivo at high rates, which results in the rapid turnover of CD4 cells. These findings, along with others, suggest that AIDS should not be considered a separate entity from HIV infection, that current reliance on reverse transcriptase inhibitors needs to be re-evaluated, and that HIV-related opportunistic infections need to be prevented. As more becomes known about HIV, Lison concludes, it is important to refrain from concentrating on one strategy to the exclusion of others, and that whatever preventative strategies are developed are useful to the millions of infected persons as well.

ACCESS TO INFORMATION AND SERVICE PROVISION

The Haemophilia Society and Birchgrove Group have commissioned a short term study into the provision of information and services for people directly affected by HIV and haemophilia.

We would be grateful if you could help us in this stage of the study. We are keen to ensure that the questions we ask of those who provide services, whether that be social workers, haemophilia centres or local voluntary sector HIV organisations, are relevant to the experience of people living with HIV and haemophilia, their partners and other carers.

We have identified 'key' areas which it seems sensible to investigate. We would be grateful if you could think about the following points, as an individual, or as part of any group or network in which you may be involved. We would also be keen to hear if there are other issues which you think ought to be addressed as part of this study and we will do our best to incorporate them into future work.

- It appears that there is very little printed information available which reflects, or is targeted at, HIV positive Haemophiliacs, or their partners, families or carers. Two areas of concern which have been mentioned are the information needs for 'long term survivors'; and information for those who wish to have children.
- As part of the project, we would like to ascertain, if and how, "Care in the Community" is working. We realise that there may be discrepancies between the theory and people's own experiences, and that there may be problems with effective and sensitive service provision.
- It has been said that some Haemophilia Centres are not fully conversant with all HIV related treatments and care issues. There appears to be reluctance in some areas to co-ordinate or consult with HIV specialists. Bearing in mind the long and particularly "intense" relationship between people with haemophilia and haemophilia centres, this area is likely to be complex.
- A final area of concern is the role and contribution that HIV dedicated voluntary organisations are making and/or could make in the provision of information and services for those affected by both haemophilia and HIV. When making recommendations regarding development of service provision, it is important that HIV dedicated voluntary organisations are considered.

We have focussed on just four areas identified as important in information and service provision. If you think that there are other areas that should be considered, please let us know.

please help!

I am looking for people who are willing to help by sharing their experiences and opinions. Please could you help us by answering some questions over the phone. The subjects that I am particularly interested in are listed opposite.

I hope that you can help us with this study. We appreciate that this request may come 'out of the blue', but I very much hope that you will be able to respond.

Please telephone: 0345 69723 and leave your phone number and I will call you back as soon as possible. Or, if you would prefer, write to P.O. Box 313, Canterbury, Kent CT1 1GL. and I will get in contact.

Thanks for your help.

Stephanie Sexton

I am willing to help by sharing my experiences and opinions.

Name:

Address:.....

.....

.....

Postcode:

Telephone:

The Haemophilia Society
123 Westminster Bridge Road,
London SE1 7HR
Telephone: 0171 928 2020



The Birchgrove Group
P.O.Box 313, Canterbury,
Kent CT1 1GL.
Telephone: 0345 697231



BIRCHGROVE IS A FORUM FOR:

- The treatments 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

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 feelings and confronting the issues directly
- Have needs that are best understood by drawing on the experiences of those in the same situation
- 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

Available from the Birchgrove Group, free of charge are the following information leaflets and back issues of the Birchgrove Newsletter.

Birchgrove Newsletter Back Issues

- BIRCHGROVE newsletter Issue 3
- BIRCHGROVE newsletter Issue 4
- BIRCHGROVE newsletter Issue 5
- BIRCHGROVE newsletter Issue 6

Birchgrove Information Leaflets

- HIV and Itchy skin
- An ABC of Hepatitis
- Liver Disease and HIV
- HIV and Vitamins & Minerals
- Glossary of terms

We can also supply the following items.

- "Living with Haemophilia and HIV" £2.50
- Red Ribbons (Cloth) 50
- Red Ribbon Badges (Enamel) £2.50
- Birchgrove Red Ribbons (Enamel) £2.50

Name:

.....

Address:

.....

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Send to: The Birchgrove Group,
PO Box 313, Canterbury Kent CT1 1 GL
or phone Lo-Call 0345 697231

THE 'TOTALLY SUBJECTIVE' CONDOM SURVEY

We asked a number of brave volunteers to "road test" a number of different condoms and give us some feedback on their performance. This is by no means a comprehensive or scientific survey and the responses are all totally subjective! We asked the following questions: Was it easy to open? Was it easy to put on? How did it smell? Was it well lubricated? How was the fit? Please describe its sensitivity? Would you use this make again?

Out of a possible total of 24 points the clear loser was Yorkshire Tradings "Red Stripe" with a total of only 8 points. It scored the minimum in all categories except "ease of putting it on", where it achieved an average rating. Other poorly rated condoms were the Durex "Jeans" and "Ultra Strong", scoring 9 and 9.5 respectively. The Ultra Safe was the only plain ended condom in our survey, and although this may have helped the fit, its sensitivity was described as "as subtle as a Marigold Glove!"

The Durex "Extra Safe" was rated 12, suggesting a rather mundane and boring condom, and provoking two contrasting opinions. One volunteer complained "it gave me an itchy dick" and another stated that with some "fine tuning, it could be a winner." Better again was the Durex "Safe Play", scoring 16 points, doing particularly well for "ease of opening" and "ease of fit". The Femidom scored poorly, apart from the lubrication which was described as "wet enough to sink a battleship". One volunteer compared his experience of using a Femidom as "trying to make love to a Ham Sandwich".

And so to our top three condom recommendations. Joint equal with a score of 19, the Terrence Higgins Trust condom and the Jiffi "Cocktail" both scored very well in all categories except "ease of putting on" where they were only rated as average. The "Cocktail" condom was described as "going well with ice cream" (You not supposed to eat it! then again maybe you are?).

The top scoring condom in our mini survey, was Jiffi's "Gold", scoring top marks in all categories apart from smell where it was described as "uninspiring" and "reminiscent of a wet inner-tube". One volunteer remarked that though "it was not as tasty as the Cocktail, but it was comfortable and sensitive nonetheless". Overall our winning condom scored 19.5 points. So there you have it, Birchgrove says, "Go for Gold".