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The Birchgrove

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JOURNEY TO THE THIRD WORLD

Continued on Back Page

Recently Chen Chunling, a visiting professor from Shanghai, China, attended an Information Day sponsored by the Haemophilia Society of Southern California. Chen, the mother of an 11-year-old son with severe haemophilia, had previously met only one other person with haemophilia.

But today, among those she met were frequent PEN contributor Paul Clement and his 11-year-old-son Brett, who has severe haemophilia A. Paul and his friends talked with Chen for over an hour. What he learned about her struggles, and about inadequate haemophilia care in China, he admits, "made our problems-like getting a single lot in the size we want-seem insignificant."Like many children with haemophilia in developing countries, Chen's son has chronic joint problems, lives in isolation from any haemophilia community, and spends much of his life in bed. Unlike many children, Chen's son can get factor concentrates because he lives in a large city.

But he receives factor for only his most severe bleeds-the kind that keep a child awake all night in agony. When Chen saw Brett and the other boys with severe haemophilia running and playing, she broke into tears.Surprised and moved, Paul and his friends vowed to help Chen. Says Paul,"She touched our hearts. "Throughout the world, thousands of children with haemophilia suffer each day with crippling and painful bleeds. Many still die. In the U.S., we take for granted that we have access to factor, any time of day with just a phone call, and often remain unaware of the tragedies unfolding in our world wide haemophilia community.

When Chen witnessed the state of American haemophilia care, her eyes opened to the possibilities for her son. When you learn about the state of care in the developing world, you too will dream of possibilities, and ask How can I help ? We've all seen the face of the Third World-in advertisements, charity appeals, or news reports of political crises or natural disasters in Rwanda,Somalia, Kosovo or Honduras. We are aware of the compounded impact of malnutrition, lack of education and infrastructure, hunger and unemployment.To be born into this world with haemophilia almost guarantees a life of pain,crippling, dependency and isolation.

Laurie Kelley, PEN editor and author, visited hospitals, haemophilia organisations and patients in five developing countries earlier this year, as part of her work for The Leadership Institute for Global Haemophilia Training (L.I.G.H.T.). She was stunned at the contrast between haemophilia treatment in the U.S. and third world countries."We cannot imagine the lives that these families live," says Kelley. "I meta child in Russia who was paralysed permanently from the waist down from aspinal bleed at age six. I met two preteen brothers from the Dominican Republic with permanent nerve and muscle damage in their feet, preventing them from walking-they had no wheelchairs, so their father carried them on his back. I visited a clinic where the doctor had to send parents home with no more treatment than an instruction to apply ice and avoid using flimsy sandals for a four-year-old-as he bled into his ankle, right before our eyes.

"In El Salvador, Kelley visited the home of ten-year-old Elmer, who shares aone-room shack with his mother and 17-year-old sister, hours from a city.Small for his age from apparent malnutrition, and crippled by repeated bleeds, Elmer has dropped out of school. He is illiterate, and his future looks dim. His mother, Doris, earns about $30 a month selling vegetables door-to-door. They have no electricity, no plumbing, no windows-and certainly no factor. "Everything Elmer's family owns," says Kelley, "could fit into a laundry basket. With no postal address or means of communication,to the outside world Elmer barely exists."The collapse of the financial system in Russia last year has put a virtual freeze on government purchases of factor concentrate-but even in good times,factor was only for those under age 18, living in one of four major cities.

Those living outside major cities like Moscow or St. Petersburg must rely,like patients in many countries, on fresh frozen plasma or cryoprecipitate,when available. Still, the wait for an ambulance is long, as is the wait for plasma in the hospital. Patients may wait hours for treatment, and in that time much damage is done.For one little boy in Zimbabwe this summer, help came too late. An untreated bleed in his leg caused severe tissue damage, then gangrene. He barely survived the operation to amputate his leg. And for Shere Khan, an eight-year-old from Pakistan, there was no help. A head injury-treatable in the U.S.-led to his death, just four months before Kelley visited his father in April.

"This is not the only tragedy for this family," she says. "This is the second child they have lost to haemophilia. With the father and his one remaining son sitting before me, I could see what was going through this man's mind-Will this also happen to my last surviving son?"State of the World Of the estimated 350,000 people in the world with severe or moderate haemophilia A1, nearly 80% have no access to clotting factor. It is predicted that by the year 2020, 550,000 people will require replacement therapy for haemophilia2, most of them in developing countries.

This means that at the present rate, almost 440,000 people will go untreated.The 20% who currently do receive treatment live in developed countries: the United States, Canada, Australia, New Zealand and most of Europe. Developing countries, like Zimbabwe and Nicaragua, use cryoprecipitate. Due to inadequate transfusion services and lack of technology, little factor concentrate is produced in developing countries."The major problem faced by the haemophilia community in Pakistan is then on-

MAINLINERS HCV CONFERENCE

BY R. OAKLEY CONT ON INSIDE PAGE

In November I attended Mainliners International Hepatitis C Conference in Amsterdam. Mainliners are an agency working with and for people affected by drugs and blood borne viruses. They are based in London and the conference was held in partnership with Mainline (Dutch equivalent), The Dutch Hepatitis Information Centre and The European Monitoring Centre for Drugs and Drug addiction.

Delegates were mainly drawn from the UK and Holland and represented many different organisations including health trusts, hospitals, drug agencies, probation service, prisons and government departments. A number of people living with and affected by the virus also went to the conference.

I wanted to attend the conference for mainly personal reasons, I have been living with HIV and Hepatitis C (HCV) for many years and also run a support group (The Hat Trick Group) for people living with and affected by haemophilia and HIV. The majority of people who access the group are also HCV positive.

I was joined at the conference by three friends, one in the same position as myself and the other a woman with haemophilia and HCV who was accompanied by her husband. Apart from learning about HCV we all supported each other and had a great time in the evenings, although most of our social conversation was about work! The experience would not have been the same without you guys.

History of the Conference and the Global Picture of HCV

This was the fifth year Mainliners International Hepatitis C Conference has been held, the first outside of the UK. Globally there is a growing awareness of the situation, in the UK small but practical advances in support and research are ongoing.

It is estimated that 3% of the world's population are infected with HCV, which is 170 million people. Of these 5 million live in Western Europe and the rate of new infections is between 1 and 3 people per 100,000 annually .In some countries the rate of infection is declining due to greater awareness and information, although our knowledge is increasing there are still many uncertainties and questions to be asked. Not least amongst the dilemmas are questions around treatment, Basil Williams (Director Mainliners) informed delegates that general European protocol is to not treat drug users and until recently the policy in France was to not treat anyone who came into the following categories: ' older and younger people ', drug/alcohol users and/or HIV co-infected. Thanks in part to ' Act Up Paris ' attitudes in that country are slowly changing. Some of the moral outcry reminds me of the situation with HIV a number of years back. Have we not learned that lesson?

The situation in developed countries is, as usual, not mirrored in developing nations. The rate of infection is greater in such countries through needle-stick injuries, blood/blood products, prenatal exposure and some rituals including circumcision and scarification. Access to treatments is governed by finance and in developing countries treatment for HCV is not an issue as there are no treatments.

One country that is getting its act to-gether in response to HCV is Australia, evidence and examples of their response were to be seen and heard over the weekend. Nick Crofts (Mc Farlane Burnet Centre for Medical Research) is one of many Australians exploring the issues. He informed us that the prevalence of the virus is less in Australia largely due to a health promotion message of ' be blood aware '. This message encourages people to find out how HCV is transmitted and make informed decisions based on that knowledge. Easy, I hear you say. How many people in the UK understand how HCV is transmitted? What do people who have access to such knowledge do with the information? Research has found that HCV has been round for thousands of years, and by testing stored blood samples the virus had infected many gay men in Australia before HIV. Although Australia is a leading light around research and information it remains a political issue and is often seen as only a problem for injecting drug users (IDU). Heard that one before as well.

Sex and Drugs and HCV

Those old chestnuts again! This part of the day's proceedings was tackled by Dr William Rosenberg (Southampton Hospital, England). Obviously we cannot protect ourselves and inform others if we do not understand how the virus is transmitted, it is important to have this information in order to avoid scapegoating groups in society and for developing good health promotion strategies. An American study was discussed that put forward the proposition that sexual transmission was the cause of 16% of cases. Dr Rosenberg and others were convinced the study was not representative and had been poorly researched, the consensus was that this study meant very little. From my understanding the study was done on IDU's of which 75% were HCV positive anyway. Reliable studies have found a ' small chance of HCV being passed on sexually '. Research using people with haemophilia and HCV in heterosexual ' stable ' relationships for upwards of 13 years found transmission rates of 4%. The risk of mother to baby transmission is 3 to 4%.

These studies highlight the need for good counselling concentrating on the risks of transmission and people wanting to have children. The main routes of transmission remain blood to blood contact and in developing countries blood/blood products and re-use of unsterile medical equipment. The sharing of any drug using equipment (needles, syringes/other paraphernalia) remains a high-risk activity if done so with a person who is infected. In answer to the question of why many people are still sharing drug using paraphernalia two reasons put forward were that users thought it was safe to share with a particular person or they had forgotten/lost their own equipment.

Many of speakers addressed the challenges facing IDU's and various agencies response to these issues, for further and more detailed information please contact Mainliners:020 7582 5434

http://members.aol.com/linersmain

Living with HCV

One of the most moving and honest presentations of the conference came from three people living with the virus; each had 10 to 15 minutes to talk about their own challenges and experiences. To my great surprise and delight the last speaker was my friend with haemophilia! She had not told us and I was so pleased to hear her speaking. All three speakers shared similar experiences and it must have been pretty scary standing up in front of so many people and sharing such personal information. Issues around haemophilia were certainly brought home to delegates, just as well because we found many health professionals did not come to the conference knowing much about the haemophilia community. All three on the panel told us how they faced discrimination and shared worries about money, illness and lack of knowledge from other people. A highlighted the issues that arise with family life, protecting family members from infection, earning enough money, sharing personal

HCV CONFERENCE CONTINUED

called ' Quality Adjusted Life Years ' shortened to QALY! This determines the cost benefit of treatment and 'life years saved '. The results of this system show that combination therapy drug treatment for HCV is very effective and is cost effective with long term financial savings, in other words a ' no brainer '.

HCV and transplantation

Prof. Dr Peter LM Jansen who is Dutch covered issues around transplantation and all figures relate to his studies in The Netherlands. When a person has HCV and chirosis of the liver they are considered appropriate for transplantation, it is best to perform surgery when the patient is as well as possible. The liver does not regenerate and if damaged to the rate of 57% transplantation is considered necessary. In Holland the cause of chirrosis is found to be 50% virus related and 50% due to alcohol consumption. In 8 years survival rate is up to 85%.

The virus does not go away and a new liver will become re-infected in nearly 100% of cases, disease recurrence is 30% over 30 years. In other words a new liver will slowly fail. It could give you another thirty years of life though. Factors affecting disease progression includes HCV genotype, HCV RNA titre (don't ask) number of acute rejection episodes and the type of immunosuppression used after surgery. Over five years people with HCV do no worse than people transplanted for other reasons but longer term convincing data is needed. Combination therapy is used after transplantation but 43% of people were withdrawn due to side effects, in this trial 20% of people remained clear of the virus. It is expected liver transplants will be on the increase in the next decade because of the catch up effect of liver deterioration due to HCV infection. This will have an effect on waiting lists and it is important better immunosuppression schemes are formulated. The general outcome of these findings is that we must be looking to new therapeutic approaches including vaccination schemes, immunoglobuline therapy and triple anti-viral therapy.

A short interlude to meet colleagues from The Netherlands

My friend and I (who was representing The National Birchgrove Group) noticed two members of The Netherlands Haemophilia Society on the delegate list. We thought it a good idea to make ourselves known and compare notes, finding issues and strategies we might have in common. Well. We had lunch to-gether and agreed to disagree on our different approaches to the challenges people living with haemophilia face. My friend pointed out various cultural differences and we left it at that!

The Radical Approach

Act Up are an activist group who respond to issues faced by HIV positive people. They have set up a new group for co-infected people. Many positive people are subjected to injustice and Act Up believe in acting with purpose to challenge other peoples perceptions and actions. In France it is only recently that HCV positive drug users have been recognised as human beings and the issues for gay men have followed a similar path. Act Up often take direct action and do not favour the sensitive, controlled approach.

I often feel that pwh and HIV and/or HCV would be listened to more if we took a similar approach, you can be polite and patient for so long and I sometimes look at where we are today and wonder, have we actually gained anything? I am talking about recognition from government and society for the great injustice that has been done. Many, many years after contaminated blood was prescribed for use by trusting, unsuspecting ' patients 'and we still have to struggle financially. Many of us have died, many more will surely die in the future and the viruses we have are affecting people all the time. Polite lobbying of government, writing to media, the feeling that we are forgotten and societies general disinterest unless it happens to them. I sometimes get fed up and feel like ' acting up '. It's not surprising.

However, to end on a high, I really enjoyed the conference and would rather you took this away when reading my account. I learned a lot and enjoyed myself, re-affirming my desire to live my life in spite of what has happened and support others in doing the same.

The last speaker at the conference was Joey Trancina, a big bear of a man from the good ol' US of A. Joey runs the Hepatitis C Global Foundation. The foundation believe in helping people do things for themselves, finding out what we can do for others in the same situation. They run a global communications network and, in typical American style, are planning a global concert to highlight the issues bought up by HCV.

So, that is my report. I hope it was understandable and interesting. It remains for me to mention that The Haemophilia Society are hosting an HCV Co-Infection Conference in London in spring of 2001. Anyone with concerns regarding HCV; HIV or indeed co-infection pleases contact Lucy McGrath or Babs Evans at The Society.

Finally, thanks to 'the gay icon ' and my other two friends who helped make this trip the fun it was.

Also thanks to my co-sponsors: The Haemophilia Society The Macfarlane Trust and Roche UK.

Richard

GRAB YOUR PURPLE HAT [illegible]

A women looks in the mirror:

Age 3 - Looks at herself and sees a Queen!

Age 8 - Looks at herself and sees herself as Cinderella / Sleeping Beauty / Cheerleader,

Age 14- Looks at herself and if she is PMS'ing sees Fat / Pimples / Ugly, "Mom I can't go to school looking like this!"

Age 20 - Looks at herself and sees"too fat / too thin, too short / tall, Too straight/curly," but decides she's going anyway.

Age 30 - Looks at herself and sees"too fat / thin, too short / tall, too straight / curly" - but decides she doesn't have time to fix it so she's going anyway.

Age 40 - Looks at herself and sees "too fat/thin, too short/tall, too straight / curly" - but says, "at least, I'm clean" and goes anyway.

Age 50 - Looks at herself and sees "I am" and goes wherever she wants to go.

Age 60 - Looks at herself and reminds herself of all the people who can't even see themselves in the mirror anymore. Goes out and conquers the world.

Age 70 - Looks at herself & sees wisdom, laughter and ability, goes out and enjoys life.

Age 80 - Doesn't bother to look. Just puts on a purple hat and goes out to have fun with the world.

Send this on to all the women you are grateful to have as friends We should all grab that purple hat a little earlier! Perhaps you would like to put into Birchgrove Newsletter for all the girls

Jan Wallace (friend of Birchgrove)

DISCLAIMER

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ALL-PARTY PARLIAMENTARY GROUP ON AIDS

International attention

The international HIV crisis has had a high profile over the summer. The International AIDS Conference in Durban in July was widely-reported, helped by the controversial views of President Mbeki. It heard about falling prevalence in Uganda and about hopes for vaccine and microbicide development. Dr Evan Harris MP, a member of the APPG AIDS, has become one of the first UK volunteers to test the safety of possible vaccine candidates. HIV has been discussed at the highest-level gatherings, including the G8 Summit, the UN Millennium Summit, the UN Security Council, the Southern African Development Community and European Commission, usually in the context of other diseases of poverty. However, specific funding pledges have not been made. The Mbeki controversy has been fuelled by news that South African MPs are receiving anti-retrovirals to which the population has no access (Sunday Times 8 Oct).

G8 Summit

In the run-up to the G8 Summit, Neil Gerrard MP, Chair of the APPG AIDS, asked Tony Blair to ensure that the industrialised countries make an increased contribution to the addressing the poverty that fuels the HIV crisis in Africa (Oral PQ 12 July). After the Summit, the PM made a statement announcing the G8's commitment to the international development target to reduce HIV infections (Hansard 24 July).

Select Committee Inquiry

The International Development Select Committee has finished taking evidence for its Inquiry into HIV/AIDS. Witnesses included Peter Piot, Alan Whiteside nd Clare Short.and the report is expected later this year. Simon Wright, Policy Adviser to the All-Party Parliamentary Group on AIDS has been appointed as Specialist Adviser to the Committee for the remainder of the Inquiry.

Joined-up thinking

Dr Jenny Tonge, Liberal Democrat spokesperson on international development asked DFID what recent discussions it had had on HIV with the Foreign Office, Defence and Trade Departments. Clare Short said there was ongoing dialogue, for instance in preparation for the G8 Summit and on Trade Related Aspects on Property Rights affecting drugs costs

Drugs pricing

Lord Rea asked whether price monopolies among pharmaceutical companies would be reviewed, in light of the high costs of HIV and hepatitis drugs. LordHunt of King's Heath said that prices are at a similar levels elsewhere in Europe and the Pharmaceutical Price Regulation Scheme ensures that overall costs are kept reasonable.

Funding

Gary Streeter MP (above), Conservative International Development spokesman, asked Clare Short MP how much money her department has spent on HIV/AIDS since 1992. In her answer, Clare Short said there had been an increase from £15m in 1992-93, £41m in 1996-97 to £55m in 1999-2000 (Commons PQ 24 July).

Strategy Timetable

The English Dept of Health's draft Sexual Health and HIV Strategy is now expected to be released by the end of the year. A date for the All-Party Parliamentary Group on AIDS's planned consultation session on the HIV elements is now being sought for January.

NGO Funding

Viscount Craigavon asked DFID about restrictions to the funding of reproductive health NGOs. Baroness Amos replied that the overall funding would not decrease although the rules are changing so that NGOs must raise a proportion of their funding from elsewhere (Lords, 10 July).

APPG AIDS Meetings

The last meeting of the All-Party Parliamentary Group on AIDS before the summer recess heard Chris Puplick, Chair of Australian National Council on AIDS Australia's four national strategies for HIV/AIDS since 1989. The first meeting after the recess will hear about employment discrimination. Speakers will include Mark Hedley, who won his case for unfair dismissal against Aldi.

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MAINLINERS FIFTH INTERNATIONAL HCV CONFERENCE CONT

information, what to do if taking medication with possible side effects and a hundred and one other challenges. Panellists from the UK had major concerns about accessing treatment; often your postcode determines your treatment options. Our very own representative explained how people with haemophilia (pwh) were infected and the way in which we were told , how HCV affects family life including the financial impact it has, how she decided to tell people about her status and the positive way in which her friends and family took the news. She also recognised that sharing this with people worked out well for her but other people find it scary and choose to keep it secret. The UK government's refusal to announce a full public enquiry and consider financial recompense was met with some astonishment from the floor. Thank you to my friend with haemophilia who was brave and eloquent, you will be able to read a full account of her thoughts elsewhere in The Haemophilia Society Bulletin.

By this time in the proceedings it was the end of day one, the haemophilia delegation set out to find Indonesian cuisine and Dutch beverages, needless to say we were successful and managed to wind down in preparation for a good nights sleep and clear head in the morning.

What we know now and what does the Future hold…

Dr Graham Foster started the ball rolling on Saturday. Dr Foster is from St Mary's Hospital in London and he described how, over the last ten years, we are beginning to slowly understand HCV. The main objective is to engineer a vaccine, this usually involves taking part of a virus and injecting it into a patient, the anti-bodies of that bit then bind themselves to the virus in the body and neutralise it. The problem with HCV is that the virus mutates so any anti-bodies used in a vaccine would not work. Apparently HCV's receptor is the key and as soon as we find out how that works a vaccine should be possible. Dr Foster seemed quietly confident that ' the next few years should see a vaccine getting nearer '. Let's hope so.

One question hepatologists are looking at closely is why some people seem to remain well even if infected, over a thirty year period 30% of infected people can be expected to suffer liver damage, some people are exposed to the virus but anti-bodies disappear. It may have something to do with which type of HCV they were exposed to, different strains are called genotypes and tests can determine which genotype an individual has. The Human Genome Project (basically a map of how the human body is made) is proving helpful in the search for which genes determine the outcome of HCV. As the virus affects the liver it would seem sensible to conclude that an individuals lifestyle has a bearing on progression of illness in people with the virus. This would include consumption of alcohol and other drugs. However in studies of patient groups some people who are teetotal have still gone on to develop illness while others have not. It is thought some people may be predisposed to symptoms and others not.

An interesting point was put forward that says HCV is not just a virus that affects the liver, scans on patients suggest the virus may well affect the brain which would explain the extreme fatigue some people get when infected.

Treatment

Although treatment options are wider than a few years ago many Doctors at the conference felt current therapy is ' not good enough '. The rate of success stands at 40%, not bad but needs to be improved. Therapy is poorly tolerated and the side effects can be awful. The two drugs in use are INTERFERON and RIBAVIRIN; these are often used to-gether hence the term COMBINATION THERAPY. Work on improving both these drugs is ongoing and some progress is being made. A new interferon is on the market; it is called PEGYLATED INTEFERON and is taken once a week instead of three times a week for the old drug. It seems to be working better than the old drugs when used on its own (mono-therapy) but still not as good as results using combination therapy. Basically work continues to find the best possible therapy and I found the details very complicated!

As for the future, delegates were advised to counsel people living with the virus to not ignore that fact, we will probably find out what genes individuals have and how that affects treatment regimes. The consensus seems to be that a vaccine is ' not terribly far away ' and to keep up to date with whats happening.

Co-infection

For many people with haemophilia and HIV this is the big question…how does HCV affect the other virus we have been living with for twenty odd years. Most of the information at the conference, while clinically complicated, spelt out individuals options fairly clearly. Co-infection is not so simple. Co-infection in this case means being infected with more than one virus; most pwh and HIV also live with HCV, HepA and HepB. Nigel Hughes (NHS Strategist HCV with Roche Products, England) welcomed us to his presentation with the warning 'co-infection is an extremely complicated issue'. In Western Europe 33% of HIV positive people also have HCV, a low estimate of pwh and HIV also having HCV is 60-85%. I say a low estimate because it is probably more but no one really knows. Within these studies 6% of tested samples were false negatives. Co-infection complicates clinical management and results in excess morbidity and mortality. Co-infected people are at increased risk from active HCV related liver disease. Statistically you are 70% more likely to die a virus-related death if you are co-infected over mono HCV infected. Heard enough? Yes, so have I. I feel very frightened writing this and hope anyone co-infected is not realising these facts for the first time. Statistics can be misleading and my personal feeling is that we are all individuals and can take steps to remain healthy and not get depressed about what I have just written. I would like to see the Prime Minister and his buddies sit through this part of the conference and then explain why it's not a problem to me in the bar later.

Treating Co-infection

I would point out at that not all HIV/HCV positive people choose to have treatment, it is an individual choice, which should be decided upon once armed with good information and support. Unless of course you become so ill that treatment becomes the only option. If you are co-infected all the viruses can interact with eachother and some can even reconstitute themselves, so if, for instance Hep B has remained dormant, it can come back again due to other viruses present in the body. The more viruses you have the harder it is to treat and they may interact against the combination therapy. The plan when treating co-infection is to stabilise HIV, then move on to treat HCV. This calls for a major commitment by the person infected and should be individualised; each person is different and what works for one may not for another. A major problem I see is the many different physicians an individual would need to talk with, it can be hard enough finding an HIV doctor you trust, then a hepatologist comes into the picture and maybe a haemophilia consultant. All this and then you may need all three of them to sit down with you and discuss treatment options. It is interesting that many pwh and HCV who have died recently did so from damaged livers, and we were all told that HCV was ' nothing much to probably worry about '. Sorry, I want to be up beat about co-infection but don't think I have been. The latest results concerning treatment of co-infected people do make less depressing reading; these can be obtained from The Haemophilia Society, please contact Lucy Mc Grath or Babs Evans at the office for further information. For my own part I remain positive about the future and while not denying many people are ill and have died I am in touch with many co-infected people who live very positive, fulfilling and happy lives.

The cost of treating HCV

All medical intervention costs money, and anti-HCV combination therapy is no different. However if no one were treated for HCV it would mean a loss of 3.1 million lives per year worldwide. What is probably more relevant is how to compare the cost effectiveness of treatment. This is done by a system

TO USE IT OR NOT, THAT IS THE QUESTION

Over the last year or so I have been meeting many people with haemophilia and HIV/HCV, discussing shared challenges and problems. Whilst this has been of much benefit to me I have found one aspect of our lives that is very different. I was surprised that most of the guys (and they all are) that I chat to have taken the decision to use as little blood clotting treatment as possible. I say surprised because I use factor on a prophylactic basis and made the assumption that many other people did the same. Although I don't stick a needle in my veins for fun I am determined to never again experience the pain and frustration that comes with a bleed. Therefore I inject myself every other day in order to live a bleed free life. I would like to state at this point that I recognise each individual's choice around their treatment options and am not saying my way is right and others wrong, it just interests me.

Ironically I was just coming to terms with haemophilia when I was diagnosed HIV+ at 29 years of age. Yes it took me a long time and it was a struggle but I had finally realised that I did not have to put up with the pain of a bleed and had begun to treat myself and talk to other people about my condition. I used to live with bleeds as I had done all through my childhood and refused to use factor until it was too late and the pain had begun. Learning to treat myself on a prophylactic basis took most of that pain and uncertainty away and I probably went too far the other way, treating myself more than I needed to, it became almost an addiction.

When I was told I had tested positive for HIV I don't remember treating myself less although that doesn't mean I didn't worry about what was in the syringes at the time, I did. With the lack of knowledge and support from my centre at that time I just assumed it was too late to do anything, the bad blood had got into me and what harm could I do to myself now. The centre staff stuck to the mantra of the benefits outweighing the possible dangers, no mention of HCV of course, they just let history repeat itself.

I do remember being given heat-treated product when it became available and feeling relieved as I assumed this was totally safe. Well I say assumed, I was told it was. And now I am battling to get recombinant factor as everyone says it is better. If you look at the issues closely though recombinant still uses human cells or it would not work properly. So, whats the difference? A new recombinant product is due out soon so those of you fighting for this product beware when you get it; it could well be the old one that nobody wants!

As I said earlier many of the men I talk to have made the decision not to treat themselves for many reasons. They reason that their livers have to put up with enough abuse already from the anti HIV/HCV combinations and I can understand that. Also the risk of further infection with varying strains of HIV and CJD are constant worries although our Doctors say its safe to use nowadays.

Well, will we ever believe them again? It is not very nice injecting yourself with crap as we all know and it is a constant reminder of what has happened and may happen in the future, I wonder what it is like for those of you with inhibitors, if I think I use a lot of factor Christ knows how you all feel.

I know that my centres policy with newly diagnosed children is to encourage treatment and most parents accept this, I sincerely hope that kids born with haemophilia don't have to go through the pain I experienced as a child but wonder if those parents would still want their children treated with factor if they had half an hours chat with one of us. Some women carriers still have terminations if a scan shows they are pregnant with a male child. How does that make you feel? So, I would be interested in other peoples feelings about this, how often do you use factor, how safe do you feel about your product, do you still get bleeds, is recombinant the saviour, write in and let me know.

In closing I would like to say that although I still stick that needle in me I feel weird every time I do it, and always wonder what they will find in me next.

Please send all comments to Editor@birchgrovegroup.org.uk

Partnership Meeting

Thursday 10th Aug 2000

Being very new to actually meeting face to face with the MFT,as for so many yrs you only had access to anyone via the phone,my excitement at the prospect of actually being able to have a proper voice for the first time was initially exciting. This excitement did`t last.It was as if the ghost of John Williams still pervaded over all,a favourite line he frequently spouted ''If registrants find out about something they can claim for they will claim regardless of need'' Peter stevens is without doubt a very well educated man although I`m unsure as to who`s best interests he has in mind.

Mr Stevens was granted a meeting with Lord Hunt to explain the MFT was going to have to spend more money quicker in the very near future,Lord Hunt was concerned that this may cause problems although he would look into providing the money.WHY oh WHY is Lord Hunt so overly concerned that registrants are asking for some form of help from the MFT when there maybe a local authority, or even another charity we could seek assistance from first?.Should we really have to do this I wonder.Approaching the MFT even now is hard enough without the thought of having to go elsewhere.Wont some one please protect our annonimity from organisations we shouldn't`t need to contact and disclose our status,thus saving any unneeded stress and worry,PLEASE

Each and every registrants circumstances are going to be different,we are after all individuals with many and varied changing needs.If Lord Hunt feels the Govt dept hasn't`t kept a closer eye on the way the MFT has spent monies,so much so he is thinking of putting in a civil servant to look into this as soon as possible.

Perhaps Lord Hunt feels we shouldn't`t still be here,let alone asking or even pleading for our voice and needs to be met. I`m sure more registrant would gladly meet with the MFT Trustee`s to talk given an opportunity.So many issues are being discussed,sadly to hear Peter Stevens comment upon how we need to streamline the amount of registrants for further meetings due to the expense was disappointing. The lights maybe on at the MFT,but is anyone really paying any attention,or are they just working hand in glove with Govt Dept`s to cut back as much as they can.Thus making life more complicated and frustrating than actually needs be.

Attendee

THE NEEDLE AND THE DAMAGE DONE

After reading Richards article "Factor 8 to use it or not, that is the question" in the last edition of The Birchgrove I was left asking myself a lot of questions about how I use or have used factor myself.

We are all people living with Haemophilia and all use factor to combat our bleeds but Richard makes a very important remark in that it is only when you start talking to other people in the same situation you begin to realise that we all have different ideas about our very same treatment for the very same disorder.

None of us want to experience pain from joint bleeds and the subsequent damage it inflicts on the joints but is taking factor that easy?

When this "wonder drug" began to be used in UK Haemophilia centres I was only a child and I very soon developed inhibitors. These varied in percentages but were always present throughout my teenage years and eventually disappeared in my early twenties around the time I was diagnosed HIV+.

As a result of the inhibitors, sometimes after treatment for one bleed the inhibitors grew so high that treatment for a successive bleed would be useless. It did not matter how much factor I was injected with, the bleeds still continued. This left me with target joints that bled throughout my childhood and teens and it came to the point where I wouldn't treat myself and instead opt for a week or two on the sofa and in discomfort. I was repeatedly reminded by my Doctors that if my inhibitor levels rose though constant factor 8 use then I would have problems if I ever had to face urgent surgery. Prophylactic use of factor 8 was never an option.

I use factor now whenever I need it and that is normally when I know I have a bleed starting. I also sometimes just can't be bothered to give myself an injection. I just think the whole process is boring, which is a ridiculous notion compared with the tedium of being immobilised by a joint bleed, but that is how I feel sometimes.

I also think that my veins are pretty important and I do try and conserve them as best I can. Having already lost the function of a couple of veins in my arms due to hospital interventions and not having the most prominent veins to start with I feel that this is something to consider.

I also have a deep fear every time I give myself factor that I am pumping some new weird virus or infection into my already virally infected body and this sometimes makes me reluctant to use factor especially for minor bleeds.

When I read the small print on the carefully folded up information sheets inside the boxes of Fanhdi (the factor I am given by my hospital, not the factor of my choice) it states that:

"The viral removal/inactivation procedures may be of limited value against non-enveloped viruses such as hepatitis A virus or parovirus B19 and other transmissible agents"

"The plasma used in the manufacture of this product has been collected from remunerated US donors"

"The transmission of infectious agents cannot be totally excluded"

"....the risk of blood-borne infections being passed on by the product cannot be completely eliminated."

"Patients receiving Factor 8 concentrates should be vaccinated against Hepatitis A and B."

Are these not reasons enough to give me fears about using factor on a regular basis or even at all? These warnings must certainly give Grifols, the manufacturer and distributor of Fanhdi, some legal security but it doesn't give me any confidence or faith in their product.

So how do the people receiving recombinant feel? Do they treat more regularly given a sense that their treatment really is safe now? Or are you waiting for the second-generation recombinants with no added human albumin before you will shoot up with no worries?

The bottom line is that I have been exposed to and infected with Australian antigen, Hepatitis B and C and HIV all via NHS supplied contaminated factor 8 and I am, by chance, still alive and I don't want to compromise my life any further with any new infections.

The other reality that I live with is that because factor was useless due to my inhibitors and because I have been reluctant to use factor regularly due to psychological fears I now have chronic arthritis in both knees and an ankle due to constant untreated bleeds and have mobility problems.

So its yet another gamble that we have to take, to use it or not.

If I could have access to the new, safer recombinant factor then my attitude may well change but whilst English health authorities still refuse to give us the best treatment available we are still at risk of further infections and contamination.

In my experience it seems that the horse has already bolted and still the stable door is not being shut properly.

Mr. B I O'Hazard

Dear The Guardian

Re: Sufferers share "safer" blood to beat rationing / Anger of victim who waits for the post

So the Department of Health do not advise any patient to take any medication not specifically prescribed for them as it can be extremely dangerous. Andy 36 is like all other Haemophiliacs in the UK who have taken the medication prescribed to them, namely blood derived Factor VIII, and over 1200 contracted HIV and over 4000 have contracted HCV from that medication alone. Over 800 of these NHS patients have now died and many live with severe illness and compromised lifestyles. Surely nothing could be more dangerous than taking that prescribed contaminated clotting factor.

Successive governments have refused a Public Inquiry into this scandal, have refused no fault recompense payments to victims of Hepatitis C, and adults that are already infected in England have no choice but to continue injecting blood derived Factor VIII that states on its packaging that transmission of infectious agents, such as hepatitis A and parvovirus B19 cannot be totally excluded. There is a theoretical risk of nvCJD being passed on by blood products and fear of contracting BSE is also a real concern for all people with Haemophilia.

It is no wonder Andy illegally accepts recombinant Factor VIII through a covert underground network as it could save his life.

Yours

Paul Bateman

BIRCHGROVE IS A FORUM FOR:

- The treatments of haemophilia and HIV
- Taking care of ourselves, through informed debate and argument
- Staying healthy with Haemophilia HIV & AIDS and HEP C
- 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
- 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

availability of quality blood products-properly screened, preserved FFPs, or cryoprecipitates," says Dr. A. S. Chughtai, Associate Professor of Pathology at King Edward Medical College in Lahore, Pakistan. "The cost of factor concentrates is out of reach of 95% of our patients."

Dr. Ehsanullah, a pathologist in Karachi, reports, "About 2% of people in Pakistan are considered well-to-do. These elite receive their education and health care in the West. They can afford to pay. About20% are middle class. They live in real agony, because they know what they have, what they ought to have, and what they can't get for their kids." Here calls the grim choice of one father whose child had thalessemia. When asked to get 25 shots of Desferal every month for his child, this father said, "'Doctor, I cannot let other children and the whole family starve for the sake of one. Let this one die.'"The tragedy of unobtainable factor is compounded by poverty, unemployment,illiteracy, lack of information about bleeding disorders, and limited access to health care.

In Lahore, for example, the literacy rate is only 35%. "Lack of awareness and education of the patients about their disease is a problem," explains Dr. Chughtai. "Treatment is either erratic, delayed or incorrect because patients do not know exactly where to go for treatment. As a result, all sorts of complications occur at a fairly early stage of development." Lack of information about haemophilia encourages powerlessness and dependency, with patients conditioned not to question highly educated and powerful doctors. Dr. Ehsanullah concludes sadly, "Most of our people-78%-live miserable lives. "Cultural practices in developing nations have an impact on haemophilia care.In Pakistan and India, the custom of inter family marriage has led to a higher rate of haemophilia, and higher prevalence of its rarer forms-like factor 13 deficiency, which many doctors don't understand how to treat.

"Th e medical community in most parts of Pakistan is neither sufficiently motivated nor organised to look at haemophilia as a problem of much significance," admits Dr. Chughtai. Yet, he adds, "This is probably because there are other major medical problems to tackle, such as immunisation,malnourishment, tuberculosis, diarrhoea and infections."Religious beliefs and superstitions also affect attitudes toward haemophilia,and prevent many from seeking proper treatment. In some countries,haemophilia is considered a shame; fathers often blame mothers. One mother in St. Petersburg, Russia, believes that the divorce rate in Russia among couples with a child with haemophilia is well over 40%.Some adhere to the ancient idea that haemophilia is a curse, caused by evildone in earlier generations.

One Pakistani mother with six children, three with haemophilia, was told by the local shaman that haemophilia in her family was brought by an "evil spirit." She was advised to cut off a goat's head and hang it in her son's bedroom to absorb the evil spirit. In the morning,she was to throw away the goat's head. Her son would be cured. If literate and poor, this mother may have followed her shaman's advice, but thanks to her contact with the recently formed local haemophilia society, she had received education about haemophilia, and knew the shaman's "treatment" would not cure her son.Basic Resources: Doctors and Hospitals Many haematologists from developing countries study abroad, in developed countries, where facilities are excellent and resources abundant.

When these physicians return home, bearing knowledge and expertise to help their people, they often must work in deplorable conditions. Many work different shifts in two or three hospitals, or lack resources and equipment needed to adequately do their job. A tour through some of these hospitals may remind overseas visitors of American hospitals of a much earlier era: cracked tile floors, exposed rusted pipes, stifling heat, overcrowding, lack of privacy.Yet, says Laurie Kelley, some startling contrasts exist. "The new Plaza deSalud in Santo Domingo, D.R., is a huge, beautiful, clean private hospital-and empty! Private hospitals require payment out-of-pocket, and their costs are beyond the means of all but the very rich."By contrast, the 100 pediatric haemophilia patients of Dr. Rosa Nieves inSanto Domingo come only to the Robert Reid Cabral Hospital. It is a public hospital, so care is free-but factor and cryo are lacking. According to Ashok Verma, Secretary General of the Haemophilia Federation of India, "No health insurance is available for our people with haemophilia. On their own,not even 1% of people with haemophilia can afford proper care

"Despite the poor condition of hospitals, physicians who are well trained to treat haemophilia remain the most basic-and most needed-resource. "Our most immediate need," asserts Dr. Chughtai, "is for properly trained haematologists, lab technicians, nurses and physiotherapists." In somecountries, even in a city of millions it is not unusual to find only one haematologist adequately trained to treat haemophilia. "With a population of almost one billion," says Verma, "India must have about 50,000 people with severe haemophilia, all needing full or partial support. Caring for them requires immense resources ."Physicians worry about lack of factor concentrate and inadequately trained staff, but also, as one might expect, about medical complications of treatment, such as hepatitis and a contaminated blood supply. Finding donorsis always a problem, since many countries do not strongly encourage blooddonations; donor blood may be inadequately screened; and the ability to screen for hepatitis and HIV may be lacking."In many countries cryoprecipitate is the standard therapy for haemophilia,"writes Brian O'Mahony, President of the World Federation of Haemophilia (WFH).

"In some of these countries, donors are not screened for HIV orhepatitis C, so there is a significant risk of infection."3 Continues O'Mahony, "The lifetime risk of developing HIV infection for a person with severe haemophilia using cryoprecipitate is 3 per cent in the U.S.A. and 40per cent in Venezuela."4 Many countries have a staggering rate of hepatitis among the haemophilia population-as high as 90% in Nicaragua, where the oldest living person with haemophilia is only 47.

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