

Birchgrove

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Drugs-“Can’t live with them, Can’t live without them”

No Rock’n’Roll, just a little bit of Sex, but loads of Drugs. Since Birchgrove’s last Drugs issue the HIV drugs scene has changed, hepatitis drugs have changed and societies perceptions towards some controlled drugs have also changed. Through successful drug use people with HIV are living longer and have different outlooks towards the future. This has implications with people’s lifestyle choices both with HIV drugs and wider use of medicinal and social drugs. With the advent of highly active anti-retrovirals the drug options open to most people are much improved from the days of monotherapy AZT. With 6 Nucleoside analogues, 2 non-nucleoside reverse transcriptase inhibitors, 7 protease inhibitors and 1 nucleotide analogue to choose from, together with other trial options of drugs such as T20 there are now around 90 different combinations that people may be on. For some, drug resistance may mean that some, or most of these are no longer an option, but for the other treatment naive “the world’s your oyster” compared with, say, 10 years ago. Issues around salvage therapy drugs are growing, as is the importance of being informed about treatment choices. But what if your only chance of getting the right drug is on a trial? Do you know how to access these and ask the right questions?

Whether they work or not, love them or hate them, drugs will always be a part of our lives and at the least we have the luxury of being offered them unlike some developing countries. HIV aside we all live our varied lives and most of use and consume other drugs in

social and recreational settings whether it be coffee, beer, cigarettes, cannabis or cocaine, to name only a few examples. Other drugs such as painkillers or anti-inflammatory’s are common amongst people with Haemophilia and with arthritis. Interferon and Ribavirin is a classic example of the varied cocktails that some of us are expected to consume. Mix these up with your anti-biotics, anti-histamines, anti-depressants, anti-emetics, sleeping pills and inhalers and still try and work out what time it is that you are supposed to eat.

In this issue we hope to explore some of these topics through readers stories, experiences and perspectives, conference reports and information blatantly plagiarised from other sources. We hope this will give an insight of both current HIV drug options and the impact of social drugs and how they affect us as individuals.

Next Issue - Complementary Medicine and Alternative Therapies.

If you have any personal accounts of using complimentary or alternative therapies or medicines that you would like to share with other readers please send to birchgrove1@hotmail.com or post to Birchgrove PO Box 9755 Solihull, B92 9WA before the 6th September.

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SPLIFF ME UP

Last year BBC 1's Panorama showed a programme entitled "Cannabis from the Chemist" which looked at medical trials involving cannabis for a wide range of medical uses. Dr Philip Robson medical director of the Clinical Trials stated in the programme that cannabis could help a number of conditions such as M.S., spinal conditions, inflammatory conditions such as Arthritis, HIV and Aids and cancer and also may have uses in mental illness. On the same programme Professor Lester Grinspoon MD of Harvard University stated that cannabis was the "wonder drug of the future".

For what some people perceive as a harmless weed, Cannabis has been used both recreationally and medically and has been well documented for the last 4000 years.

Last year the BMJ investigated its usefulness in a medical setting. Mo Mowlem called for the legalisation of cannabis. Peter Lilly was quoted as stating that "outlawing cannabis is indefensible" and Canada legalised cannabis for medical use indicating a changing tide in opinions to this drug.

The medical trial specifically looked at MS sufferers and gave them various types of cannabis preparations including a placebo to try. Rather than giving the patient the weed or resin in its natural form these preparations come in the form of inhalers and oral sprays and this is what the pharmaceuticals are looking at as a future drug option if and when cannabis is legalised in the UK. The companies producing cannabis derived medication however, perceive the "high" associated with cannabis use as undesirable and one of the main aims of the trial is to see if the cannabis does have a beneficial effect on the patient without getting them "high".

Dr Willy Notcutt (James Paget Memorial Hospital Gt. Yarmouth) refers to the "high" and argues that for someone with lifelong debilitating chronic illness to be denied the right to feel high, happier and mellow is unjust. He went on to say that "mind-altering anti depressants such as Prozac are prescribed at the drop of a hat, so why should the moral ground on cannabis be any different?"

Prof. Mike Barnes from the University of Newcastle upon Tyne, also on panorama, suggests that his MS patients try cannabis if they have had no success with orthodox medicines. He believes that cannabis may have many uses for people with chronic illness.

The trial's outcome was very positive and the main point seemed to be that getting the dose right for each individual was the most important issue. The patients studied said that after a while they got used to taking enough to give a beneficial effect, i.e. pain relief, mobility without getting completely stoned. This was complicated by the fact that all patients noted that the preparation that worked the best was the one that had the highest content of THC, the main psychoactive chemical found in cannabis.

With regard to medical availability Prof Lester Grinspoon puts the point across that as medical marijuana becomes legal and the wider population notice the positive effects, they will in turn change their own notions and ideas about the negative toxicity and illegality of this benign drug.

The only place I know of where you can legally and easily purchase and smoke Cannabis is in Holland and mainly in the coffee shops of Amsterdam. Here, menu's will offer a wide range of grasses including Purple Haze, Orange bud, Skunk, super skunk, Hindu Kush, Northern lights, Buddha, Thai Stick, White Widow, Sensimilla, Shiva and AK47. Hash or resins include the much-revered Nepalese Temple Ball, Double zero, Afghani, Pakistani and Indian black, Moroccan and Lebanese. All these varieties are, as to the wine lover and the grape, very different to each other and are indicative of their region of origin.

Cannabis enhances perception especially with music and visual images. It stimulates the appetite or gives the "munchies" and stimulates thirst. It also gives an increased sense of empathy, peacefulness, relaxation and sexual stimulation. It relaxes the body muscles and eases pain as it has analgesic properties. Its anti-emetic properties help control nausea and it can help with hiccups. It also enhances deep sleep and can help with glaucoma. It enhances your mood and if used socially can induce fits of giggles or at the least a mild high.

If there was ever a drug that was suited to alleviate problems with Haemophilia, HIV, HCV and arthritis then cannabis is the one for me. With bleeds, a spliff eases pain helps me sleep and takes the monotony out of lying on the sofa all day. It's anti-inflammatory properties and analgesic effects help with my arthritic joints. With my HIV again I feel that a good nights sleep is essential to my well-being and it certainly helps there. The nausea and other side effects from HIV medication are

**"O thou weed!
Who are so
lovely fair and
smell'st so
sweet
That the sense
aches at thee,
wouldst thou
hads't ne'er
been born"**

**William
Shakespeare**

SPLIFF ME UP

relieved with cannabis. A joint gives me the munchies and helps with regular eating and snacking essential again to my health. It also gets me high and I think with my baggage I need to have some avenue of release and I enjoy its effects. With my HCV, doctors are constantly reinforcing the message to stop drinking so how do I kick back at the weekend or wind down after a heavy session at the hospital. Most normal people just go and get pissed but as an adult I would prefer to get stoned.

I spoke to my specialist nurse about my cannabis use and she said that if I needed something to get me through difficult times then she would lots rather it be a few spliffs than a few pints. My HIV specialist also was sympathetic and admitted that over 50% of his patients have been open about their cannabis use and there are no known contra-indications with HIV medication.

Cannabis is usually smoked and mixed with tobacco in a spliff or joint. Obviously this is no good for people who do not like smoking and although it can be smoked neat through a pipe or water pipe (bong) this may not suit anybody who has had a PCP infection (although there are claims that cannabis can work as a bronchial dilator). Diluted in hot water as a tea, swallowed or eaten in home made cakes and confectionary are the normal preferred options for non-smokers but until you know your own balance with this drug eating it can be unpredictable as once you have eaten too much there's no going back.

The MMCO (medical marijuana co-operative) are an organisation that illegally sends cannabis and marijuana to patients who have a medical need. All you have to do is supply a supporting letter from your GP or consultant verifying your condition and they will hopefully supply your needs. Their web site however does stress not to use their PO Box address as Manchester Police are opening their mail first so I don't know how risky this is.

As Cannabis is illegal, scoring can often lead to hanging about in places you wouldn't normally choose, unless you live in Brixton already, if you don't have a reputable regular main man. Other options are home growing either in a greenhouse, or artificially with a grow-light kit in a wardrobe or with hydroponics system all advertised in a wide range of magazines such as Loaded or Viz.

Cannabis can make the user feel paranoid or anxious depending on their mood or their situation. It can also affect short-term memory loss and ability to concentrate and make judgments. This may be an important point with regard to HIV drug adherence. If you are

stoned will you remember to take your pills? As it affects co-ordination it may increase the risks of accidents and impair driving. If these are concerns for you then it might be best giving it a miss as it affects everybody differently. One of the worst associated problems is that it is usually smoked with tobacco, and a tobacco addiction can be fatal as the government keeps pointing out on the packets. Another risk with street drugs is that they are often cut, and cannabis is no exception, with poorer quality resins being the worst offender. Anything from henna, tars, melted down vinyl and plastics are sometimes added which should cause health concerns especially when smoked. If you do not have a reputable supplier then Grass is less unadulterated but beware some of the super strength hydroponic buds, especially for the novice, as they can be extremely strong and should be treated with caution. It is also still illegal in the UK at present and a criminal conviction is a lot more harmful and long lasting than any effect the drug can ever have. Personal possession is seen as a caution in most parts of the UK now but if you buy in bulk (to save cash, and cut down on time spent in seedy pubs meeting dodgy geezers for deals) or happen to have an allotment or greenhouse full you could run the risk of being perceived as a dealer which carries far harsher penalties.

One day I hope the British injustice system will see sense and the medical use of this herb will not still render me a criminal.

Whether you use Cannabis already or not it shouldn't be discounted as something to try if it can help with any of the problems associated with our conditions and if it is enjoyable at the same time then I think we are due some high times.

But be careful, because only users lose drugs.

The Silver-Backed Gorilla

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Fabulous Furry Freak Brothers comics

www.mmco.org.uk

www.schmoo.co.uk

When I first had to get my head around starting HIV medication it felt like a bloody minefield, but one of the biggest things I had to come to terms with was popping pills each and every day for the rest of my life. I have never been big on swallowing pills and only have ever taken painkillers when I have really needed them. The concept of actually having to remember and take a handful of pills each day freaked me out to say the least. Four years down the line and it is still something I struggle with and do not take for granted. I am hopeless without my diary pill box as I can never remember whether I have taken my pills or not as it has become so habitual. The other problem is remembering to fill the pill box up each week. If it's at a weekend and I'm busy I get lazy and just pop them out the packets for a few days before wondering whether I have or haven't taken them. Also the early morning pills seem to be the hardest to sort out, as I'm not the sharpest tool in the box first thing. Having to actually wake up on time can be a burden at times, and to start the day with pills can sometimes be tricky, especially if nauseas. I once woke up took my pills, forgot I had taken them and then took them again. I realised as soon as I had swallowed them. I tried to spew them up by sticking my fingers down my throat, without success and then in a mad panic about toxic overload took a handful of senocot in the hope it would flush them through my system a bit quicker. Big mistake. I spent most of the morning and day worrying myself stupid and then the latter part of the day and evening sat on the bog.

Mornings I feel also can be unpredictable times. The postman wakes you to sign for something, it ruins the routine and before you know it its time for the evening's pills and the mornings ones are still in the box.

I know that medical advice is that good adherence is the best way to get the pills to do their job and helps to reduce the risks of resistance. Following my combination regimen exactly is the best chance I have of getting them to work and to work for a long time. But I live in the real world and life doesn't always follow a nice smooth exact pattern.

I also know that good practice should be that clinics provide adherence support for patients. Back to the real world. I had to argue for a pill box from my pharmacy when I started treatment as they said they weren't supposed to give them out. What the f*ck where they supposed to be doing with them? I think a lot of doctors assume that Haemophilia patients are used to medication and self-administering drugs and generally self-assessing our medical needs, so we aren't perceived as adherence failures. I once asked to see an adherence advisor but was told these are only normally used for I.V. drug users and alcoholics who have erratic lifestyles. Show me anybody who lives with Haemophilia, HIV and HCV who doesn't have an erratic lifestyle.

Should the MFT provide us with state of the art multi timer watches and decent radio alarm clocks with Goblin teas-made to facilitate our pill popping? Has anyone claimed for this and got it? I am sure there is a medical need.

On the other hand I don't know how I would feel about my watch bleeping if I was in the company of people who know nothing about my HIV and tablet munching. I don't want to draw attention to myself when I am trying to neck my pills covertly.

I suppose the beauty of the morning regime is that it is largely done in private as opposed to evening pills when there is more chance of being in company. When out in the evenings I used to pop outside for "a breath of fresh air" or go to a toilet cubicle to swallow them in private. These days I am more open about this and feel that most people do not notice. Either that or I have perfected the art of slipping pills out of my pocket, into my mouth and down my throat in the blink of an eye. On the times when people have asked me what I am taking I have always passed it off as painkillers and blamed my aching knees.

The other problem of taking pills out socially is that there is a real risk of having to explain your pill regimen to some ape-like pig thick bouncer who has just turned your pockets out at the door of a nightclub or pub. Hiding them in your sock or underpants might keep them safer but will only look even more sinister if some monkey in a bow tie comes across them. Individual pill dispensers are a good idea, but what do you do with them once you have taken the medication? I prefer just to stick them in my pocket.

Traveling can be problematic with adherence but unfortunately I haven't had the luxury of passing through too many time zones recently for it to be a problem. I also find the clocks changing and the light summer nights can be confusing, just as the reverse is in the winter.

The other aspect to all of this is that I look at my pills when I am filling my box up and it still doesn't feel right sometimes that these are the toxic chemicals that I am going to consume this week. There are still times when I am about to swallow my pills when I hesitate and I just don't feel like taking them. Most of the time though I seem to do OK, and I have stopped beating myself up when I have forgotten and just accepted that this is the real life and I don't live in a clinical trial.

**8TH ANNUAL
BRITISH HIV
ASSOCIATION
(BHIVA)
CONFERENCE**

19th 21st April
2002

This year's annual BHIVA conference was held at the University of York and included speakers from the UK, Europe, the USA and Australia who gave presentations on a wide range of issues around HIV. I attended as a representative of Hat-Trick group, which secured a place at the conference through BHIVA's community delegate allocation.

After the chairman's welcome the conference kicked off at a fast pace which it resumed throughout the 3 days.

GIGA HAART therapy was the first subject on the agenda in patients whose drug regimen was failing them and had progressive disease. Two cohorts of patients were looked at specifically using up to 9 different drugs within one regimen per patient. One group started straight away and the other group had an 8-week "drug holiday" before starting. The results in the group that had the 2-month rest from drugs had the better response rates and less HIV related illness, although the long term success and toxicity of such regimes were uncalculated. This also opens the debate as to whether Health Authorities would be happy funding such a costly cocktail.

Dr Ranjabahu Kulasegaram (St Thomas's Hospital, London) gave an overview of HIV/HCV co-infection. Although the prognosis of co-infected to develop liver cirrhosis was higher than HCV infected individuals Dr Kulasegaram stated that by maintaining a high CD4 count and cutting out alcohol the prognosis could be brought to the same level of HCV mono infected. He emphasised that people with haemophilia should have transjugular biopsies under factor VIII cover as this was less invasive from a point of bleeding problems. He pointed out that physicians should be aware of all possible drug interactions such as Ribavirin combined with AZT resulting in an aemia and other warning signs such as CD4 reduction, lactic acidosis, mitochondrial toxicity and pancreatitis. For the best decisions to be made it was vital that a co-infection team in each treatment hospital was established instead of the individual seeing different specialists in different departments and clinics. This presentation provoked a discussion around funding for co-infected patients as Professor Brian Gazzard (Chelsea and Westminster Hospital, London) pointed out the difficulties of obtaining funding for HCV genotype tests, which he perceived as vital information needed by specialists and patients deciding on whether to take HCV treatment.

The symposium on "New Fill" looked at the recent developments in plastic surgery for people with facial lipodystrophy. HIV drug interactions and side effects can produce facial wasting, which adds to the distress of the patient. Dr Ed Wilkins and Dr Graham Moyle discussed whether there is now some relief for these patients? Issues around whether plastic surgery should have a valid place in HIV care was discussed but many more questions were raised.

Who will fund this product? Who decides which patients can access this treatment? Is this the only option open to patients? Is this the best product available? Which doctors will have experience of using it? Who will take responsibility to administer the treatment?

Dr Paul Slade from Bristol-Myers Squibb talked about "looking to the future" and the production of once daily NRTI's. There are a few that will be available soon and many more in the pipeline. Taking fewer drugs means that there is a chance of better adherence and patient lifestyle. There are aims to minimise the short and long-term toxicities of drugs and refinements to NNRTI's such as Sustiva, which will soon be available as one smaller 600mg pill as opposed to two larger 300mg pills. Dr Slade talked about the use of Integrase Inhibitors and their future use across a wider patient spectrum.

Dr Margaret Johnson presented a case study on HIV/Hepatitis B co-infection and highlighted the difficulties of trying to get some transplant centres to accept patients with HIV, despite a much-improved prognosis as a result of HAART and recent successes. HBV progression was quoted as being 25% higher in HIV/HBV coinfected but the good news was that there are treatments in the pipeline, which include nucleoside analogues and monoclonal antibodies.

Prof. Philippa Easterbrook (Guy's, Kings and St. Thomas's School of Medicine) gave a refreshing presentation on "Long Term Non-Progressors" in which she discussed longevity. Some people have a natural disposition to long life and this may be attributable to LTNP's. Studies with the Pumani prostitutes in Africa who remain HIV- despite continuous exposure to the virus give hope that some people do have natural resistance to the virus. Studies have shown that there is a median of 10 years from infection of HIV to an AIDS defining illness and yet 3% of patients in a European study still did not progress after this time. Reasons given were complete chance, genetic factors and the influence of other host factors on disease progression.

Positive mental attitude was the most common reported attribute to LTNP's who all had low plasma viral load and preserved lymph functions. Specific amino acid variations have been identified in LTNP's and certain mutant allele confirm resistance to HIV progression. Also Cytotoxic T Lymphocytes have found to play an important role as LTNP's exhibit more vigorous CTL activity. Studies in this area only give more hope that a vaccine for HIV will one day be available.

The next generation of Protease Inhibitors was presented by Dr Neil Graham and DR M-P de Bethune. The main reasons for wanting to improve PI's were mainly that the adherence was difficult, there was a prevalence of resistance and multi PI class resistance. Toxicity and incomplete

suppression of the virus were also valid reasons why today's PI's are far from perfect. The presentation looked at future improvements, which should take into account an increased potency that gives complete HIV suppression including hidden reservoirs in the body. The new drugs need to overcome the resistance, have an improved pill burden to improve convenience and tolerability and also to be less toxic.

Abstract presentations throughout the weekend included a study that looked at Patients who had used HAART since 1996 and which amongst other findings discovered that 64% of the study group were still living today despite most being NRTI experienced at the start of the study.

The changing population cost of HIV services showed an increase in the amount of people accessing HIV services and medication and exhibited a need for increased resources to maintain current standards of care. With the average persons lifetime of HIV drugs estimated at £135000 there has to be some forward planning by commissioners.

Drug resistant mutations in newly infected individuals was explored and concluded that mutations were more likely to be passed on with HIV infection in semen to blood rather than in blood-to-blood, which is not as significant.

Adherence was an issue covered by R.Horne from University of Brighton, which looked at the correlation between patient's own beliefs about HAART before commencing treatment and adherence. The study showed that the more doubts a patient had before starting treatment the higher the chance that they did not adhere to the regimen. This highlighted the need for more patient support and information and to ensure that each patient was fully aware of the importance of adherence. Doubts about the necessity to start treatment and the concerns about the adverse effects were common patient concerns. Health professionals should try to find solutions to help patients overcome their anxieties and doubts and implement strategies that enhance adherence.

The abstract on testicular cancer had me clutching my gonads as it stated that there was a higher incidence amongst HIV+ men. In the study the majority of patients diagnosed early responded well to, and tolerated, chemotherapy and radiotherapy but the treatment adversely affected the CD4 counts.

Another looked at patients with CD4 counts below 100 and argued the ease in patients who were CMV + that CMV viral load tests were a more significant indicator to the patient's health than either the CD4 or viral load test. Patients who had high CMV loads had a faster progression to mortality.

An abstract by AH Mohsen looked at the progression rate of liver fibrosis in the HIV/HCV coinfectd. Rates of progression to fibrosis were higher in this group and had higher rates of inflammation despite a reduction in alcohol. Estimated time from co-infection to cirrhosis was around 22 years compared with 32 years in HCV infected only and the other contributory factor to fibrosis progression was a low CD4 count.

S Hopkins discussed HCV therapy in HIV/HCV+ patients and reiterated that genotype 1 was a poor responder to treatment. He pointed out that although the treatment was difficult to take for most patients alongside their HIV medication, that clinicians should avoid dose reduction if possible. He also stressed the need for psychiatric intervention before and during HCV therapy to assist in supporting the patient.

There was also exhibited throughout the weekend the poster presentations which included presentations on lipodystrophy, nevirapine rash, cardiac conditions, herpes, cancers, stool analysis, facial lipoatrophy, thyroid disease, pain management and to top it all a graphic presentation of an autopsy which put a few people off their rack of lamb at dinner that night.

Although the conference was very professional based and laced with medical terminology and jargon, graphs and charts that sent me dizzy and subject matter that was far from light hearted it was worthwhile attending for the knowledge that I acquired. Meeting other organisations, drug reps and people working in the many aspects of the world of HIV is always invaluable and also gives an opportunity to share experiences. By working together with other organisations, community groups such as Hat Trick and Birchgrove attending these kind of events, only help to forward our own cause and gives an opportunity for others in "the business" to understand our particular needs.

For a full report on all the presentations visit www.aidsmap.com or more information about BHIVA visit www.bhiva.org

I would like to thank Babs Evans (Haemophilia Society) and Esther Mosinghi (Positively Women) who shared a stand at the conference and promoted Birchgrove material.

**8TH ANNUAL
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Cocaine and HIV

Cocaine is a stimulant made from the leaves of the South American coca shrub. It comes in the form of a white powder costing between £30 and £100 per gram. Usually snorted into the nose, it provides a feeling of excitement, exhilaration and self-confidence lasting for about 15 to 30 minutes.

Cocaine is not metabolised by the body in the same way as anti-HIV drugs so there does not appear to be cause for concern about interactions between them.

Test-tube studies suggest that cocaine alters the functioning of the immune system in several ways, making immune cells more vulnerable to HIV. Experiments conducted in HIV infected mice bred in laboratories, found that mice exposed to cocaine had far fewer CD4 T cells than mice not given the drug. This suggests that HIV disease may progress faster in regular cocaine users.

In common with most other street drugs, users are rarely sold a pure form of cocaine. The drug is often "cut" with other cheaper drugs such as amphetamines (speed), talc or detergents, which can be poisonous or create irritation, leading to infection.

Snorting cocaine can damage the membranes between the nostrils, leading to bleeding and eventual erosion. There have been reports that sharing snorting equipment may permit the transmission of hepatitis C virus.

As with all recreational drugs it is also wise to consider how use could impact on adherence to your HIV treatments.

Taken from nam factsheet 64 - April 2002

More E's less T's

Ecstasy zaps T-cells

A survey of 17 HIV negative men published in the *Lancet* has found that one dose of ecstasy causes a 30 per cent decline in T-cells, and that two doses reduce them by 40 per cent. The numbers return to normal within a day of taking one pill, but a double dose continues to depress their numbers well after 24 hours.

First published Positive Nation May 2002

"Putting The Drugs Trials on Trial"

UK Community Advisory Board (CAB) and Treatment Advocates Network

HIV i-Base is a treatment activist group, which is HIV positive lead and committed to providing timely HIV treatment information both to healthcare professionals and to positive people themselves. i-Base was formed in April 2002 by the publications, editorial and meetings team from the former AIDS Treatment Project and they aim to cover the medical advances in HIV and AIDS through their publications, meetings, phone line, website and information service.

i-Base recently held a meeting for the formation of a UK based forum where patient and community groups can formally meet with either research groups or the pharmaceutical industry. The intentions of the Community Advisory Board (CAB) is to be a forum for general discussion about treatment issues, ideas about trial design and a focus for community groups. Cab's are a way that ordinary, non-professional people can have some input into their healthcare at many levels. This can include planning effective trials that have better standards of care and safety, making sure patient information is clear and becoming involved in getting early access to new drugs if needed. Meeting with the pharmaceutical companies can also focus on the reality of taking their products and hopefully result in better

research and monitoring of side effects.

In the US CAB's have been established for many years and work with major government research centres and hospitals. Recently the American Treatment Activists Coalition (ATAC) has been formed so that one group of people across the US can meet with each of the companies (www.atac-usa.org/).

There has been a European CAB running for around 4 years (ECAB) and includes community activists from around 18 countries. Following this model national CAB's have been set up in Italy Spain and Germany. In France there is an umbrella group called TRT-5 which include people from the seven largest treatment focused HIV organisations and they meet with industry, Government and researchers.

The aim of the day was to bring together interested UK groups to develop a UK-CAB along similar lines and i-Base invited me along, as they are keen to have some representation from the Haemophilia community. As it happened I wasn't the only person with Haemophilia at the meeting so I didn't feel too alone.

The day started with a presentation from Douglas Newberry, Clinical Trials manager at the Medical Research Council (MRC) and Prof. Tim Peto (John Radcliffe Hospital, Oxford) on clinical trials. This looked at how trials are devised and evaluated and prompted some discussion in the meeting. Evaluating drugs through individual patient, doctor or clinical experience can be biased by the individual's own experience and feelings. Drugs can be assessed by uncontrolled observational studies such as looking at Triple combination therapy in large numbers of individuals and assessing that it works. This doesn't take into account systematic comparisons between different treatments and finding out more important information such as working out what is the minimum dose of a drug that actually works. There are many observational trials that look at different regimens and look at

certain markers such as health over a period of time, but many other factors are never entered into. The need for clinical trials was stressed by the need to ensure comparisons are precise and fair and well measured.

However there are many issues that clinical trials raise with medical ethics being only one. Will this drug work or will it make the patient worse? Who decides what is ethical? Who is allowed on the trial in the first place and who decides who is excluded? Why is there no patient representation on hospital Ethics Committees?

Overcoming random error is an issue that clinical trials have to address and the only way to overcome this is to have large numbers of individuals on a trial. Small trials have a larger degree of random error and results from trials that have only had small numbers of participants should be viewed with caution.

If you go on a trial as a patient do you know what you are letting yourself in for? If you enter a randomised trial this means that when you sign up for this trial you will not know what regimen you will be taking. It could even be a placebo and as a patient it is essential that you are prepared for this eventuality in this kind of a trial. Where placebos are concerned trials are often referred to as Single blind, where the patient is not aware what treatment he/she is taking and a double blind where the doctor as well as the patient is unaware. These kinds of trials avoid biased evaluation and are seen as essential in studies involving patient self-assessment.

How are trials designed so that they work for everybody? If a drug works in a trial on a group of HIV positive gay men over 50 years old why shouldn't it work on women in their 20's? Do trials take into account the different lifestyles and other factors particular to a sub-groups needs? Are the prescribed drug levels in pills necessary? Why should an 18 stone man have the same drug dose as a 7 stone woman? Does impaired liver function alter drug efficacy, side effects or toxicity?

In the future it should be possible for genetic testing for individuals to predict drug efficacy and side effects but until then trials are the only indicator to assess which drugs work and which drugs work best. Trials are not always accurate and can give false results so beware. Some trials focus on statistical methods to compensate for missing data due to poor follow up of patients or poor data collection. Some do not account for discontinuation of drugs due to patient choice or drug failure. The loss of patients and adverse effects of the drugs are sometimes not recorded. If you want some degree of certainty that the drugs you consume do work then maybe entering a trial is not suitable for you and as the patient and this has to be your choice. It was also pointed out that as a patient you should ask your doctor as many questions as possible before entering a trial including is your doctor being paid per patient for the trial? If so he /she may have a different agenda. Some Doctors can be career junkies and want the trial to make their name rather than cure the patient as their main objective.

London talked about informed consent and patient involvement in trials. Issues discussed were based on the essential purpose of ethical research to protect the welfare and the rights of the research participants. The medication must be beneficial and the researcher or research should do no harm to the participants. Autonomy must also be respected at all times. If you are asked to enter a trial ask if there is any other way of carrying out the research. Be aware that you can ask for all your results to be removed from the trial if you decline from the study at any time. Ethics committees meet to set up reviews regarding protocols for trials and any NHS Trust's ethics committee can change any detail in a trial as they see fit. There is no patient involvement on ethics committees and the patient is usually the last person to see the protocol of any trial.

If you decide to enter a trial it is essential that informed consent is observed. You have the right to ask why this trial is being done, why have you been chosen, do you have to take part, what will happen to you if you take part, what are the benefits that you expect to derive, will your involvement be confidential, what are the risks and disadvantages and who has reviewed the project. You can ask for the complete protocol guidelines and ask for anything to be explained that you don't understand.

Signing a consent form is also a requisite of trials. This confirms that you are a willing participant, but also protects you as well as the researchers. All consent forms should state that you can decline from the study at any time.

Ask how the research process works. How was it designed? How were samples chosen and how big is the sample size of the trial? Ask what the aim of the outcome of the trial is.

Doctors and researchers may have other reasons for recruiting participants and these may be financial incentives, access to new treatments or as a method to ensure regular medical monitoring. It could also be a research interest rather than your interest, so do be aware and be sure that entering any trial is what you really want.

One very important question to ask is that if you enter a trial, will that drug still be available to you after the trial has finished?

If you want to check out the 1962 Helsinki declaration, which has been recently reviewed then, visit www.bioscience.org/guides/declhels.htm or for further information The Consumers for Ethics in Research at www.ceres.org.uk

Gilead Sciences presented information about their company and its role with community liaison in the HIV sector. Gilead have produced the first Nucleotide RTI in "Tenofovir" which is a once daily dose and apparently has durable activity against nucleoside-resistant HIV.

Gilead also discussed their Hepatitis B drug "Adefovir". For further information about Gilead see www.gilead.com

i-Base are planning to run a number of these meetings with different pharmaceutical companies in the future. If you have any contribution to make to this please feel free to contact i-Base at the contact below, or contact Birchgrove if you want comments or issues raising on your behalf.



Paul Bateman

i-Base treatment phone line
0808 8006013
Office-0207 407 8488
Email- admin@i-Base.org.uk
www.i-Base.org.uk
Presentations from the above meeting can be viewed at www.i-base.org.uk/education/may/index.html

Drug Class	Drug Name	Brand Name
NNRTI's Non-nucleoside reverse transcriptase inhibitors	Efavirenz	<i>Sustiva</i>
	nevirapine	Viramune
NRTI's Nucleoside Analogues (nukes)	AZT, zidovudine	Retrovir
	ddi, didanosine	Videx
	ddi, didanosine -enteric coated	Videx EC
	3TC, lamivudine	EpiVir
	d4T, stavudine	Zerit
	abacavir	Ziagen
	lamivudine (3TC) + zidovudine (AZT)	Combivir
	lamivudine (3TC) + zidovudine (AZT) + abacavir	Trizivir
	zalcitabine (d4T)	Hivid
NtRTI Nucleotide Reverse Transcriptase Inhibitors	tenofovir disoproxil	Viread
PI's Protease Inhibitors	lopinavir/ritonavir	Kaletra
	indinavir	Crixivan
	nelfinavir	Viracept
	saquinavir (hard gel)	Invirase
	saquinavir (soft gel)	Fortovase
	ritonavir	Norvir
	amprenavir	Agenerase

For a pill chart showing all the licensed anti-HIV drugs in the UK, send a stamped self-addressed A4 envelope to:

...ve (drug chart), Eton House, 156 High Street, Ruislip, Middlesex HA4 8UJ

...taken from ...ve, July 2002)

THE CHAIRS DIARY *part 2*

Injection number 2.

Monday 10th December, I spend the morning getting some food in, do not want to do it after the injection as I did last week, paying off a few bills and buying a kitchen floor. (The flooring shop had a special offer). Having arranged in advance I go up to the day ward at the Elton John Centre, (the Aids ward), in Brighton. I am bothered that if I need to do the injections at home I will put them off and end up missing some whereas if I have an appointment somewhere I will go and do it. When I used to take the nebulized pentamidine monthly I found that I would put it off at home but would attend the centre if I had an appointment. The staff there are happy about me coming in and quite fascinated to see the preparation of the interferon. A co-infection clinic between them and the Gastro-enterology Department is due to start soon and they want to be able to help people cope with the interferon and its side-effects. I bring along the leaflet guiding me through the mixing and injecting procedure provided by my haemophilia centre and all the bits. Firstly I do my own factor VIII as I always find I get bruising with sub-cutaneous injections. This also gives me a chance to get my breath back after the hill climb to get here. I check that I only draw up the right amount and stick it in the left side of my stomach. Again I cannot actually feel it go in and then try and gradually push the liquid in. Naturally it does not glide in smoothly as suggested in the leaflet but I push it in **jerkily** with me pausing between to allow it to **disperse**. I pull the needle out and a wave of relief washes over me. I got it right and I can do this on my own. One of the nurses gets me a cup of tea and it tastes wonderful. I wander back down the hill home. Later that evening kitchen makers arrive and after some swearing and levering in and out of the sink my kitchen is done. I go to bed with a headache and some more paracetamol but feeling good.

Tuesday The next part of my plan to get through the six months without alcohol comes into operation as I am linked up to football TV

with what seems to be endless coverage and repeats of the league, cup and champions league on multiple sport channels. There **also** seems to be strange coverage of things I have **never** really thought of as sport; Australian women in lycra doing aerobics to high energy disco music - I wonder if this gets a bigger male audience watching than female exercising???. Bruno Brookes' fishing round-up, I never realised he had gone from bad DJ to mediocre TV host and tenpin bowling!!? This means I can chill out on a Sunday afternoon and have something to watch on a Monday night after the injections. An up morning becomes a down afternoon when I discover the pipes to the sink leak when the washing machine is on. The plumber agrees to come and look at it tomorrow. Feel a bit rubbish all day, like the first day of a cold, aches, and the cold

Wednesday, still feeling a bit fln-like but better than yesterday. A worker from the haemophilia society rings and asks me how it is going and I tell her. She asks me if I could have worked whilst taking the interferon and after thinking about I say yes. I would have been a bit rubbish at work and possibly been told to go home by colleagues but that if I had planned the injection for a Friday night by the following Monday I could have made it to work. It does feel like a great luxury not to be working whilst I am on this but if the first week really is the worst one then I am confident I can cope with the cold-like symptoms. Plumber arrives and says he needs to get a part but the shops are shut now so he will come back tomorrow. I am now in a race between with the plumber fixing it and me running out of clean clothes.

Thursday, wake up feeling fine and go off to college. Have the pleasure of telling everyone how good I feel during the last week of term. Spend the weekend alternating between football on pay-TV and seeing people and telling them what a breeze this interferon lark is. These wimps that retire to bed groaning for months at a time are just malingering. I make sure that I pile on the irony whilst saying this as I just know it will come back to haunt me. Plumber fails to materialise but appears on the Saturday with the right bit and I can wash clothes again.

The following Monday and I am back at the Elton John Centre. This time I am no longer the centre of attention and left on my own to do my two injections. I forget the explanatory leaflet but get the amount right. Fortunately the injection site of two weeks ago is so well

THE
CHAIRS
DIARY
PART 2

healed that I cannot even see where it was. I stick it in my stomach somewhere round there and hope that I can avoid the irritation and inflammation of all of the future injection sites. Once more I am greatly relieved afterwards and walk home to spend the evening in front of football. Arrange next week's appointment for a bit earlier as it is Christmas Eve. I realise that Christmas day is a Tuesday and that although that will make the not drinking alcohol part easier I did not really intend to feel bad all day as well. I think I have now worked out the stomach effects of the drugs. I believe the interferon causes diarrhoea and the ribavirin constipation so decide to alter my diet accordingly next week.

As with last week I am feeling pretty much okay by Thursday morning. The 'bind-me-up-with-bananas-and-eggs-Monday-and-Tuesday-and-extra-roughage-for-the-rest-of-the-week' diet seems to work and my stomach is fairly consistent all week. I meet a friend to go to see Eddie Izzard acting, well appearing, at the theatre in the West End. I wonder how much more culture and sport I will get to see now that pubs hold no attraction for me. I stay at another friend's new house in north London and spend the morning shopping for Christmas presents, well I go to Waterstones for some books and Tower for a couple of CDs. Then I am back at St Thomas' for my 2 week review even if it is nearly 4 weeks. Everyone seems happy that I am having so few side-effects. I pick up the next 3 packets of interferon but have to go to pharmacy for the ribavirin. Pharmacy at St Thomas has been done up since I last went to it, I tend to pick up all my drugs in Brighton now so I have not used it for a few years. I am ticked off for not having proof of income support on me, or an exemption certificate in order to get free prescriptions. I get them anyway after a half-hour wait and am then given the top copy of the script to hand in for my GP. I think about this on the way home as ribavirin is specifically listed as ineffective when prescribed on its own for hepatitis C and so I wonder what it is prescribed alone for. I look it up and discover it can be given for flu or lassa fever and as my script says nothing about the interferon I consider posting the script copy to my GP with a note stating that I have lassa fever. I decide this is not a good idea as they'd probably believe me and just add to the list of conditions already in my notes.

A good weekend for doing the rest of my present shopping but a bad one in that my team lose at home live on TV and to the team supported by a friend whose come to watch

the game. She leaves promptly after it to gloat out my earshot. Was it something I said?. Monday again and Christmas Eve as well. Mess up the interferon injection this time. Spill some of the water making the liquid more concentrated than normal and get bothered about it such that I inject awkwardly. This means for the first time I feel the needle go through the skin, it hurts, and there is a spot of blood afterwards when I withdraw it. I am glad that the staff are not watching me this time. Annoyed at myself for this and walk back home resolving to do it properly next week. Spend the day wrapping presents and feeling tired with a headache. Hit the paracetamol again and do not feel quite so good as last week. Apparently I am allowed 1 unit of alcohol per day but the thought of a third of a pint of beer or a small glass of wine really does not appeal to me. It seems so little as to be not worth bothering with and would probably only make me want to drink more. By the evening, however, I realise how much slurred drivel people talk after a days drinking. At least I get to drive home even if my passengers seem unconvinced that I have not drunk anything all day.

The next few days however I feel rather flu-like and stay in watching crap TV or sleeping. Has the more concentrated interferon this week really made such a difference or perhaps that sherry has made me feel so bad. Alcohol is supposed to make the side-effects worse so maybe it is the combination of the two. My mix and match diet for constipation and diarrhoea has not worked this week, but maybe I should have expected that. Everyone is now asking me what I have planned for New Year. I am touched by this concern for the non-drinker on the most alcoholic evening of the year until someone says that they are only trying to find out if I am driving. It is only this week that I realise that it is a Monday and so I know exactly what I will be doing. Taking drugs! Yes. I shall be taking a few paracetamol and going to bed. I probably won't even be up for news at ten never mind ringing in the New Year.

THE CHAIRS DIARY part 2

WOULD YOU LIKE TO BECOME ACTIVELY INVOLVED IN A QUALITATIVE RESEARCH STUDY?

I am currently searching for gay, bisexual and heterosexual women and men who are long-term survivors of hiv/aids who are prepared to share their perceptions and experiences of life living with hiv/aids in the uk.

The voluntary sample will include women and men who have been positively diagnosed for 10 years or more and who have had or are currently in receipt of medical treatment. I would particularly like to hear from positive women, individuals who live with a bleeding disorder and/or women and men who live with drug dependency.

If you are interested, please contact judy sagar for further details. All enquiries will be dealt with professionally and in the strictest confidence.

Tel: 07949 311041

(mobile One2One)

E-mail: JudySagar@aol.com

Address:

Ms J M Sagar

Department of

Sociology and Social Policy,

Leeds University,

LEEDS,

LS2 9JT

What does it mean to be a long-term survivor of **HIV/AIDS** in the UK?

Judy Sagar is a PhD researcher at Leeds University and is specifically looking at how long term survival with HIV has affected us from a social and psychosocial perspective. There hasn't been any research into the social affects of long term HIV infected people since 1994 and this study should take into account the changing outlook with HAART.

The social implications of the changing scientific knowledge and biomedical advances in the treatment and management of HIV is often overlooked and Judy hopes to explore these issues from our own experiences.

The interviews are preferred to be held on a face-to-face basis and take approximately an hour and a half. All interviews are recorded and copies sent back to the individual for them to give approval. No names will be used in the research and confidentiality will be observed at all times. If face-to-face interviews are not convenient then telephone interviews at a pre-arranged time can also be organised.

Judy is particularly interested in people with bleeding disorders who have been infected as well as women to give the research field a more balanced perspective, and diversity of the HIV infected individuals. If you feel you can help and have the time and energy to offload some of your experiences then Judy would be pleased to hear from you at the above contact details.

Positive Advice Legal Helpline

The UK Coalition of People Living with HIV and AIDS has launched a legal helpline to provide specialist legal advice direct to people with HIV over the telephone. Volunteer lawyers with expertise in various areas of law, such as immigration, housing, family and employment will staff the phones every Wednesday evening between 7-9pm. 020 7564 2180.

BOB THE BLEEDER

Dear Bob,
I have an alcohol problem. My elbows have become so useless with bleeds that I can no longer carry 2 four-packs of beer to my mate's house to watch the footie. I do not want to appear mean by coming empty handed. Can you help?

Tell your mates that football is no longer the working class game it once was and is now the province of the middle classes. As the fashion guru that all haemophiliacs are, you should have no trouble in getting the rest to follow your lead in sipping Chardonnay - this is not a 2nd division players wife but a type of wine and is easily available off-licences. One bottle is much easier to carry than 8 cans.

If that fails. Buy a milk maids yoke. Placing it over your shoulders you can then put the four-packs into each bucket. Since your shoulders now take the weight it should protect your elbows. It will also mean you get lots of space on the pavement as everyone else will have to swerve into the road to avoid being whacked in the stomach by one of your swinging buckets. Since the ability to carry intoxicating liquids is obviously a basic medical requirement ask your physiotherapist for a supporting letter in order to gain funds from the MacTrust for the yoke.

Dear Bob,
I would like to gain access to Traditional Chinese Medicine but the prescriptions my doctor gives are very expensive. I have used up the complementary therapies grant from the MacFarlane Trust and am not sure where I can get the money. Can you help?

This is a very sad state of affairs, outside of medical treatment from the NHS the Macfarlane Trust rarely provide for things. I, myself have long been waging a long campaign for my 'Export Super Treacle' strong lager daily requirements to be paid for by the trust. I think of it as an essential complement to my Factor VIII. Many years ago a psychiatrist stated to me that I was dependent on this substance which means that my body craves it when it is absent. Despite numerous supporting letters/threats/bills from a highly eminent Harley Street Grocer the Macfarlane Trust refuses to pay for the beer. I will however continue fighting on behalf of soaks, luses and users of complementary therapies everywhere for this.

Dear Bob,
You said us in the last issue that this one would cover drugs and I wondered if there is a risk of passing on HIV and HCV in cocaine straws?

This one has been under scrutiny for sometime but I do find the papers hard to read when I'm off my tits on Columbian happy powder. The best advice is to be safe not sorry. have some Factor before hand to avoid those annoying nosebleeds and don't share your coke straws. I have a beautifully grafted gold one with an ornate mirror which looks simply wonderful but does appear tempting for others to use. My tip to avoid this, or the bad feeling as a refusal may offend, is to keep a collection of small white plastic straws on me at all times. Smear this with tomato sauce and leave over night. The resultant dark red, lumpy goo on the straw is usually sufficient to put off anyone from sharing and if they do you can always let them keep the straw! (P.S. A good tomato sauce knocks off that bitter tang to the Charlie too).

can he fix it?

HIV man had sex with a nanny goat

A judge decided yesterday to spend two more days deciding what sentence was apt for a man spotted by commuters having sex with a nanny goat.

Stephen Hall, 23, who is HIV positive, was wrestled to the ground by walkers who found him with the animal on allotments in East Hull as the passengers, on a train to Bridlington, called the police on their mobile phones.

The commuter train had stopped at a red light, over-looking a shelter of tin sheets where Hall had imprisoned the nanny goat with his belt. Hull crown court was told that Hall had decided to assault the animal in a "spontaneous act"....

The court heard that Hall was seen having sex with the goat by a man walking with his grandson near Argyle street allotments. Hall hid but then backed into view again, with his trousers round his ankles and a tight grip on the goat....

He pleaded guilty to buggery at an earlier hearing. Rebecca Thornton, prosecuting, said the goat had suffered distress during the assault, which went on for up to ten minutes.

Martin Wainwright

The Guardian 14.03.02

We at Birchgrove understand the frustrations and complexities that HIV can bring to any meaningful sex life, and fully appreciate that people in our position have to take our opportunities when they arise. However we do recommend that any sexual partner is a consenting and willing participant especially with regard to the S+M practices. We also recommend avoiding public places such as allotments next to a busy train line and condoms and lubricants should obviously be used. Fair play to the bloke for lasting ten minutes all the same.

From HIVandhepatitis.com "Ask the experts" column.

Question:

*Does marijuana smoking
effect liver in anyway?
Can it contribute to high
liver elevations in a blood
test?*

**Answer by Ronald Baker,
PhD Ronald Baker is
publisher and editor in
chief of:
HIVandHepatitis.com**

I know of no studies that have suggested harm to the liver from marijuana, although if inhaled on a regular basis, marijuana could potentially cause lung damage.

Marijuana does not cause elevated ALT levels.

The Speaking Chair 3

Last time the magazine looked at Hepatitis C and what treatment did for you. As someone half-way through now I can assure that it gets pretty rough sometimes. I alternate between feeling fine and dreadful! Birchgrove did get represented at a number of the big conferences this year, 2 of us presented on the problems of co-infection and seeing different doctors in different hospitals and trying to get the NHS to co-ordinate this. The Haemophilia Alliance which allowed some of us to ask about the funding of "expensive patients" or, in other words, us! When will I get recombinant and why can't he get it when we live only a few miles apart?? Not being there myself I can't give you the official response to this but I bet it was not 'I'll sort that just as soon I get back to the Department of Health'. Next was the European Association Study of the Liver. 2 big Liver studies were unveiled at this conference, one by each of the 2 Interferon makers. There was also the World Federation of Haemophilia which did not unveil any great new haemophilia treatments but was a great opportunity to meet haemophiliacs from across the world. Recombinant is still children and protesters only in England, treatment of any type a nightmare to get in most countries in the world and gene therapy being talked about like recombinant was in the early 1970s. Now if only I lived in a rich country like Wales I could hope for some gene therapy in the future. Bet I'll be long dead before it's available to adults in England though.

Robert

letters/ette s/ett/ers

Resources and Information about HIV and Hepatitis

Information and support

British Liver Trust

Information, advice, support and campaigning on all aspects of liver disease including viral hepatitis (A,B,C.etc). A variety of publications and web based details.

Tel: 01473 276326

Email: info@britishlivertrust.org.uk

Website: www.britishlivertrust.org.uk

Haemophilia Society

Information, advice and support.

HIV/HCV worker Babs Evans

babs@naemophilia.org.uk

HCV worker John Morris

john@haemophilia.org.uk

Tel: 0800 018 6068

Email: info@haemophilia.org.uk

Website: www.haemophilia.org.uk

HIV and Hepatitis.com

Online publication about treatment.

Website: www.hivandhepatitis.com

Mainliners

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

Tel: 020 7582 5434

Email: linersmain@aol.com

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

National AIDS Manual

Provides up to date factual treatment information via free publications and website.

Tel: 020 7627 3200

Email: info@nam.org.uk

Website: www.aidsmap.com

The National Hepatitis C Resource Centre

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

Tel: 020 7735 7705

Email: advice&info@hap-ccentre.com

Web site: www.hep-ccentre.com

Positively Women

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

Tel: 020 7713 0222

Email: info@positivelywomen.org.uk

www.positivelywomen.org.uk

Positive Nation

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

Tel: 020 7564 2121

Email: subscriptions@positivenation.co.uk

Website: www.positivenation.co.uk

+ve

Monthly publication about HIV and quarterly issues about hepatitis

Tel: 01895 637878

Email: andrewb@akitonet.co.uk

Website: www.howsthat.co.uk

Booklets on hepatitis

A rough guide to hepatitis

Pocket-sized booklet with information about all aspects of hepatitis (from A to G).

Produced by How's That Publishing Limited

Tel: 01895 637878

Hepatitis C...meeting the challenge

Aimed at adults living with a bleeding disorder and HCV or HIV and HCV co-infection.

Produced by the Haemophilia Society.

Tel: 0800 018 6068

National Helpline Numbers

National AIDS Helpline

0800 567 123

24 hour helpline offering advice on HIV/AIDS

Terrence Higgins Trust

020 7242 1010

days per week 12-10pm Advice on HIV/AIDS

Positive Line

0800 1696806

staffed by positive people mon-fri 11am-10pm

sat/sun 4-10pm

AIDS Treatment Phone line

0845 947 0047

Treatment advice from positive people

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

National Drugs Helpline

0800 77 66 00

open 24hours

Offers free and confidential advice about any drugs issue, whether it's information, counselling or just a chat. You can also find out about services available in your area. They also provide a wide range of printed literature available on request. They also have helplines in many other languages including Welsh 0800 37 11 41 10am-2pm Mon-Sat

ADFAM National

020 7928 8900

open Monday-Friday 10am- 5pm

A national helpline for families and friends of drug users which provides confidential support and information who has concerns about someone close to them who take drugs.

Release

0207 729 9904 10am -6pm

0207 603 8654 evenings and weekends

Confidential helpline providing advice on drug use and legal issues surrounding the subject.

www.release.org.uk

Birchgrove is a Forum for:

The treatment of haemophilia and HIV

Taking best care of ourselves, through informed debate.

Staying healthy with both haemophilia and HIV/AIDS

Ways in which HIV affects love and sexuality

The social and psychological aspects of haemophilia and HIV.

We believe that people with Haemophilia and HIV...

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

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

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

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

The European Association Study of the Liver, Conference, Madrid, 2002

"Hi, Robert this is Roche Pharmaceuticals, we'd like to invite you to the EASL conference as a journalist." EASL, the European Association for the Study of The Liver, I've read about this conference and I know it is not in Britain this year but I can't remember where it is. I check, Madrid. Right so a drug company is offering me a flight, hotel accommodation and registration to the conference and all I have to do is write it up. Mmmmm moral dilemma do I accept the free trip and risk the accusation of being a drug company lackie? It's hard but someone has to be a lackie every now and then, I can always console myself with sun, Patatas Bravas, Bocquerones and a look at the Bernabeau whilst I contemplate the loss of independent credibility. Much of the conference was interesting, both big companies in the field demonstrated trial results and the weather was gorgeous. As this is a drugs issue let's talk about the drugs, Pegylated Interferon and Ribavirin. Scherring-Plough made a big thing of how their 'PEG' version gives you a specific amount calculated for how heavy you are. They, inevitably highlighted how 'weight based dosing' was a great thing, the logic that

too little is less effective in clearing the Hep C and too much gives you more side effects. They also presented some laboratory type comparisons I did not understand much. They compared their molecule with a different one that coincidentally was the one used by the other maker of 'PEG', Roche. The comparisons suggested the Scherring-Plough size molecule was better. What a surprise!

Then came Roche's turn. They were unveiling data from a big trial of about a thousand people with their drug, Pegasys and Ribavirin. They highlighted a super new high for clearing the virus in genotype 1 patients of (just) over half. They also had 1 in 4 of those classed as cirrhotic having a sustained response to the treatment. That struck me as remarkable as only a few years ago people classed as cirrhotic were told to avoid interferon for fear their liver would collapse and they could die. The classifications may be a little more generous now but it still seemed a big change to me. Roche highlighted how there was one set dose for their interferon making it easier for patients and that it was effective across a huge range of different people's weights. They then turned to their chemistry type comparisons suggesting that their molecule was better as it was heavier. They did not quite say 'our molecule is bigger than yours nyyrhr nyyrhr nur nyyrhr nur' but I was hoping. As with the other talk I got a bit lost on the bio-chemical processes of Pegylation but they did provide a great buffet to give me something to do while the scientists talked to one another.

Hepatitis B got a higher profile, which just shows what the invention of some drugs can do for a disease (Adefovir and Tenofovir), and there was lots of the 'no patients involved' sort of research in animals or tissue cultures that I did not understand much of.

In the co-infection field (either HIV and Hep C or Hep B) there was very little and one of the speakers on it did not even turn up. As with most conferences the chance to meet and talk to people from elsewhere was the best bit, apart from that walk around the Bernabeau. What a stadium! What a good thing the conference was not the following week as a bomb went off at the time I had been walking round the stadium!

Robert was funded by Roche Pharmaceuticals to attend this conference. He would like to assure the readers that he retained his independence throughout the arduous timetable of eating and drinking that Roche provided during the few days. He is also available to attend any other conferences paid for by Drug companies on condition they are interesting, warm and nice parts of the world and he is not required to do too much. Having worked as a social worker he is well versed in talking gobble-de-gook and can learn and endlessly repeat company slogans if that would help...

Robert James

Editorial Team

Mick Mason and Paul Bateman

DISCLAIMER

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

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