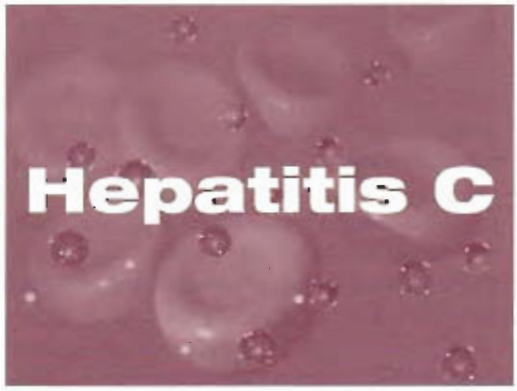
Birchgrove

Issue 3
March 2002

P.O. Box 9755
Solihull, B92 9WA

Tel: 01473 429552
Email: birchgrove1@hotmail.com



...to treat or not to treat?

It doesn't seem that long ago in the scheme of things when Doctors were telling me "don't worry about Hep. C, your HIV infection will kill you off a long time before Hep.C will ever be a problem", and " go and have a beer and try not to worry". I suppose I am lucky to be alive today and that Hepatitis C is now a worry. Hundreds of people with Haemophilia and HIV/HCV infections are no longer with us since their HCV diagnosis and maybe the doctors were right about their HIV prognosis. After living with one life threatening virus for over 17years now I have finally come to believe that I do not think that HIV will kill me, at least not for many years to come. Again I am very lucky, the HAART combination is working well and there are many future treatment options still left open to me, and I am more fortunate than people who's drugs have failed them and do not have as many options open to them. Over the last 2 years I have seen two friends pass away with end stage liver disease and it's not a pretty sight. The MFT's records show that over the last 2 years more people have died of liver disease/failure than HIV/ Aids related deaths. Its my Liver that processes the daily cocktail of drugs that I consume that are keeping me alive so I see it as a pretty important part of my well being and if HCV is going to impair my 2nd most important organ then I want rid of it if it is possible. The Pegylated Interferon/ Ribovarin looks like its as good as HCV treatment is going to get for a while so maybe this is my best shot at it. The hospital is also keen as they are getting it on the cheap through a trial. OK, so that means being a guinea pig yet again, but at least I hope there will be better monitoring during the process. The chances of success depend on who you talk to but Genotype 1 looks like being a tough little bugger to beat and I can only expect 35% chance at the best odds of the treatment working. That is if I can tolerate it. Side effects to this drug combination seem to vary incredibly from one person to the next. I have heard people say they were suicidal and couldn't take any more, to one bloke who said he felt slightly melancholy. No one knows what to expect until you start but depression, fatigue, flu symptoms, weight loss, mood changes, aggression, loss of libido and breathlessness are only some of the things to look forward to. I really have had to think hard about this as I feel well in myself, in fact better than I have for years so why go and spoil a good thing by taking something that will make me feel ill, doesn't have a good chance of success and when there is no certainty that HCV will cause me life threatening problems in the future. Also a year without alcohol, how tough will that be. I suppose such a small concern if it will save my life one day, but still unchartered territory for me to explore.

When I have met guys with Haemophilia that are PCR negative and proud, it does make me think how sweet life would be with only one life threatening virus to worry about instead of the two. I have also warned my friends and family what to expect so they don't think I am losing the plot without reason if it occurs.

After I have consulted my haematologist, hepatologist, HIV specialist, HIV pharmacist, HCV pharmacist, Haemophilia specialist nurse and Hepatology specialist nurse and I am sure that they know what they are doing I am going to start very soon. In the mean time I am eating as much as I can whenever I can and enjoying the odd beer without too much guilt.

Paul

Contents

PEGYLATED INTERFERON

What's it all about?

Pegylated Interferon has now been launched in the UK. This is not a new treatment, contrary to what appeared in the press recently. It has been undergoing trials for a number of years, mainly in people without HIV. There are 2 versions made by 2 pharmaceutical companies, Scherring-Plough and Roche. Both have shown greater success in clearing the hepatitis C virus than the standard three times a week interferon and both are to be taken in combination with Ribavirin.

How effective this Pegylated Interferon and Ribavirin combination will be in people with HIV and HCV remains to be seen. A trial looking specifically at this, and if Pegylated is significantly better in combination with Ribavirin than on its own in people with HIV and HCV, has just finished taking people on. Since the treatment lasts for one year on this trial and then each patient has to wait six months after treatment has ended and then the data has to be collected, analysed and written up it will be 2 years or so before the final results will be known. The trial is also only with the Roche version of the drug, called Pegasys, and so will not permit a comparison between the two for people with HIV and HCV. This Roche version is currently available with Ribavirin in trials only.

The Scherring-Plough version, called Peg-Intron, is however being offered by some hospitals and haemophilia centres to their patients. This should also include their patients with HIV and HCV. A number of the Birchgrove committee have been offered this Pegylated Interferon and Ribavirin combination and not just through the big London centres. Hopefully enough people will be allowed access to the treatment to compare with the trial of the Roche version.

So, how good is this for people with HIV and HCV? In terms of ease of use the pegylation process reduces the number of sub-cutanaeous injections needed from 3 every week to only 1 per week. That advantage is the same for people with HIV and HCV, however all the major work published to date is about people with HCV only. The pieces below are from trials on people with HCV only.

The company boasts a sustained virological response rate (SVR) of 54% which was obtained in clinical trials involving 1530 patients who had never before received interferon-based treatment for HCV. This compares to 47% for non-pegylated combination treatment and 12% for interferon-alone treatment. The SVR is the best measure of success, being defined as the percentage of patients continuing to be negative for the presence of the virus six months after the end of the therapy. For trial patients with genotype 1 (which affects approximately two-thirds of people with haemophilia) the SVR was only 42%, compared with 82% for the other major genotypes, 2 and 3. *(Taken from C Issues 19 with small revisions [Morris 2001])*

The number of people with genotypes 4,5 and 6 in the trial was only 44 and as they were grouped together it is not possible to give response rates for each of them.

The SVR rises to 61% for those of below average body weight who as a consequence of their lighter weight received higher amounts of ribavirin *per unit of body weight.*

Roche recently announced results from its large-scale trials of Pegasys and ribavirin, achieving a SVR of 56% (11% higher than the old combination) and 46% for genotype 1. Approval is still awaited, however, and not expected until the new year. Roche has claimed significantly reduced flu-like side-effects and incidences of depression. *(Also from C Issues 19).*

The Scherring-Plough version has to be mixed up with water, it is like going back in time for most haemophiliacs with those glass vials of water with tops that snap off and cut your finger. You mix it up gently, more gently than haemophilia factors as it froths up very easily and then inject it into stomach or thigh. The volume is tiny, less than 1ml and is slightly different for everyone depending how much they weigh. The Roche version comes ready to inject and is the same amount for everyone.

Interactions between these drugs and HIV medicines may well happen and they are being looked for in the patients currently taking the drugs and on trials. Increased chance of anaemia is one that concerns many and possibly lipo-atrophy as well. Lipo-atrophy is where you lose parts of your body fat most noticeably on the face, buttocks, arms and legs. Both of these are already side-effects of one or other of the medicines but it may be that they are more likely to occur in people taking particular HIV drugs (Stavudine and AZT have given cause for concern) and Ribavirin than in people taking medicines for only one of the viruses.

This is all very new and it is not possible to predict with any certainty who will get problems never mind what those problems will be. Careful and frequent monitoring is necessary if you want to go on this treatment as well as some trust in your doctor as s/he will be learning from what happens to you. However it does offer a chance to get rid of a virus which should make treatment of the other virus easier in the long run.

C Issues 19 is available from John Morris at The Haemophilia Society UK, Chesterfield House, 385 Euston Road, London, NW1 3AU Tel: 0800 018 6068 Email: john@haemophilia.org.uk

...it does offer a chance to get rid of a virus which should make treatment of the other virus easier in the long run

Rob (The Chair's) Treatment Diary

Day 1, Week 1 Interferon. After a few years waiting to get the combination I want for Hep C I finally get offered it by 2 hospitals at the same time. Naturally in order to start off the treatment in a relaxed way I go away for a final boozy weekend to stay with friends near Birmingham. I spend the morning on a slow but cheap train heading to Euston before my date with a needle at St Thomas'. I am nervous about this for some reason the idea of sticking a needle into my stomach bothers me, it would be so much easier just to whack it into a vein. I have finally got to the moment. I have had all the blood tests done; I know my genotype, HCV viral load, the LFTs, ALTs, ASTs gamma GTs and herbal teas.

My haemophilia doctor is surprised that I wish to start in December rather than waiting until the New Year and I explain that I actually would prefer to be able to drink in the summer rather than over Christmas and New Year. It seems a bit embarrassing to say that I had planned all this so that I could get pissed when England are knocked out of the world cup especially as she might know that the games are at 9:30 am and not 9:30pm as I thought when I made the plan. She asks have I thought about spending the time without alcohol and I think I have thought of almost nothing else but say that I intend to go out with my friends that don't drink, (a jolly mix of alcoholics, pregnant women and others on therapy). We move quickly on to when I need to come in for future appointments.

"Feel the cold most of the day and head for bed again at eight-thirty with a bit of a headache..."

The nurse goes through the procedure with me. She explains that the doctors say the side-effects come on after about six hours but that most patients have said they feel them after 1 hour. I stab myself in the belly and push the pegylated gunk in. To my surprise it does not hurt in fact I do not feel the needle at all. I pick up the tablets and head off back to the seaside full of relief. I feel okay at the station and decide to walk home rather than wait for a taxi. A friend, Mark, rings me and comes round to check I do not keel over and die that first evening which is really nice. After about 3 hours I start to get a headache but am not sure if this is because I have come down from Birmingham that day or it is a side-effect but hit the paracetamol anyway. At about nine o'clock I decide it is time to go to bed. I start to shiver and after half an hour realise I need a blanket as well as my quilt. With my teeth now chattering violently I head for the cupboard. Fuck is it cold in this house all of a sudden. Mission accomplished - blanket on bed. I am now shivering pretty badly. Another half an hour and I realise I need to pee. I don't need to describe this but it is bloody difficult pissing when your whole body is shaking but I at least have the sense to sit down rather than stand up. (Think about it!) I return to bed and after about another hour the shivering subsides. I drift off to sleep finally...I wake up wet... ...oh shit a night sweat, I move the blanket off and get back to sleep... ...chatter, chatter, so dam cold again, get the blanket shivering and drift off again... ...wake up with another sweat. I finally get to start sleeping properly at about 3 am and then sleep until 9 in the morning.

Wake up feeling not too bad and well enough to meet Mark for a coffee in town. I am feeling the draughts though this morning and return home after an hour or so calling in to get some food first. Remind myself to get food in before starting a treatment with major side-effects next time. Go home and slump on the sofa reading the paper. Feel the cold most of the day and head for bed again at eight thirty with a bit of a headache having secreted paracetamol tablets in every room of the house. Am starting to get gastro side effects now with diarrhoea and lots of wind. The wind is not trapped so it is not painful but it is not going to enhance my social standing much. Three other people ring me to ask how I am feeling on week one of the treatment and I am exhausted after the phone calls. Read a book for an hour and then sleep with only a couple of night sweats but no shivers.

Wednesday get up early as I am having my kitchen delivered today. It arrives in the morning when it is supposed to, amazing. I now have a kitchen in the living room as well as one in the kitchen. In the afternoon I have agreed to meet a new drug worker at a local project to chat about hepatitis C, which means I get to moan about how I am feeling to someone, which makes me feel lots better. I am actually feeling fairly okay just a bit hot today which I prefer to feeling cold. Check my e-mails and find 3 from friends also asking how it is going and one saying that tomorrow's lecture at college is cancelled, yippee. Again head off to bed early with a bit of a headache and paracetamol. Well I certainly won't miss boozing if keep going to bed at nine.

Thursday, sleep late and then drift potter about feeling a bit achy. Snack a bit but do not feel really very hungry. Diarrhoea is gone today, though, sadly replaced by constipation, great!

Friday and I get the 8:15 train to Croyden to get to college and see Anna who also gets this train. She tells me that I look awful and I am surprised. When I ask if I am pale or green she says no but that everything looks like it is hard work for me. I wonder what is so strange about this and does not everyone go to work or college when they feel a bit crap. Maybe I am missing out on more sick days than other people as mine are always taken up with telling doctors how well I am. College is fine if a bit cold. Quite a lot of the people ask how it is going and I say okay but I had planned a quiet week for the first one. One woman feels that my 'quiet weeks' are fuller than her busy ones. Friday is fine as is the weekend; it's not so bad this interferon - nothing like a bleed, that hurts!

Genotype and LFT's

What are they?

GENOTYPE

Genotype tests establish which strain or strains of the Hepatitis C virus are present in your blood. They are useful to the extent the genotype can be considered as an indicator of the prognosis and response to treatment. It is generally considered that genotype 2a responds better to Interferon treatment, while genotype 1b responds least. However, this conclusion should not be taken as the definite truth, as researchers can reach different conclusions in the long term. For instance, in several cases that I know of first hand, in the combination treatment of Interferon plus Ribavirin long term remission was achieved not in relation to the genotype, but in direct proportion with the frequency interferon was administered (bi-daily regimen obtaining best results even in previous non-responders to the combination treatment). Genotype therefore is probably not a good indicator of the possible outcome of treatment. Long term remission was obtained irrespective of genotype. The only indicator of the treatment outcome was the viral load AFTER commencing treatment. Thus, patients whose viral load became undetectable within 2-4 weeks from the start of treatment got the best long term remission rate (the shorter the time, the better the response, irrespective of the viral load at the commencement of treatment).

LIVER FUNCTION TESTS

The typical Liver Profile test includes ALT, AST, Alkaline Phosphatase, GGTP, Bilirubin, Prothrombin time, Protein, LDL, Albumin, and Globulin.

ALT

Alanine aminotransferase. This enzyme used to be called **S**erum **G**lutamate **P**yruvate **T**ransaminase **(SGPT)**, hence the two names. The normal range is 5-40 IU/L (International Units per Litre). Some doctors think that anything under 50 is still OK.

AST

Aspartate aminotransferase. This enzyme used to be called **S**erum **G**lutamic-**O**xaloaceti **T**ransaminase **(SGOT)**. The normal range is 5-40 IU/L. Some doctors think that anything under 50 is still OK.

AP - **A**lkaline **P**hosphatase. This enzyme level is elevated in a large number of disorders that affect the drainage of bile, such as a gallstone or tumor blocking the common bile duct, or alcoholic liver disease, or drug-induced hepatitis, blocking the flow of bile in smaller bile channels within the liver. The alkaline phosphatase is also found in other organs, such as bone, placenta, and intestine. For this reason, the GGT is utilized as a supplementary test to be sure that the elevation of alkaline phosphatase is indeed coming from the liver or the biliary tract.

GGT (or GGTP)

Gamma **G**lutamyl **T**ranspeptidase. This enzyme level is elevated in case of liver disorders.
In contrast to the alkaline phosphatase, the GGT tends not to be elevated in diseases of bone, placenta, or intestine.

Different cells have different enzymes inside them, depending on the function of the cell. Liver cells happen to have lots of AST, ALT, and GGTP inside them. When cells die or are damaged, the enzymes leak out causing the blood level of these enzymes to rise; that is why the levels of these enzymes in the blood are considered good indicators of liver cell damage.

ALT is more specific for liver disease than AST because AST is found in more types of cell (e.g. heart, intestine, muscle). The AST, for instance, will rise after a heart attack or bruised kidney. GGTP and AP are said to be more specific for evaluating biliary disease since they are made in bile duct cells. In liver disease caused by excess alcohol ingestion, the AST tends to exceed the ALT, while the reverse is true to for viral hepatitis. However, this particular generalization is often wrong.

There are several things to remember:

- These tests have a meaning, but they generally cannot be interpreted without clinical information. They are probably most useful to track, or follow a particular problem, but even then they often "bounce around" greatly.

It is generally considered that genotype 2a responds better to Interferon treatment, while genotype 1b responds least....

- These numbers are not linear. An AST that is 300 is not twice as bad as 150 (normal is less than 40), and an AST of 94 and 80 are essentially the same to a liver specialist.

- These numbers do not always detect all liver disease. Some patients with severe advanced liver disease will have normal or nearly normal enzyme levels.

Despite the fact that they are often called "liver function tests" or "LFT's", these tests do not in fact measure the liver function per se. In order to assess the liver function they must be corroborated with other tests, including albumin, bilirubin, and prothrombin time. But clinical factors should be considered as well.

Bilirubin
is the main bile pigment in humans which, when elevated, causes the yellow discoloration of the skin and eyes called jaundice. Bilirubin is formed primarily from the breakdown of a substance in red blood cells called "heme." It is taken up from blood processed through the liver, and then secreted into the bile by the liver. Normal individuals have only a small amount of bilirubin circulating in blood (less than 1.2 mg/dL). Conditions which cause increased formation of bilirubin, such as destruction of red blood cells, or decrease its removal from the blood stream, such as liver disease may result in an increase in the level of serum bilirubin. Levels greater than 3 mg/dL are usually noticeable as jaundice. The bilirubin may be elevated in many forms of liver or biliary tract disease, and thus it is also relatively nonspecific. However, serum bilirubin is generally considered a true test of liver function (LFT), since it reflects the liver's ability to take up, process, and secrete bilirubin into the bile.

Albumin
is a major protein which is produced by the liver, and chronic liver disease causes a decrease in the amount of albumin produced. Therefore, in liver disease, and particularly more advanced liver disease, the level of the serum albumin is reduced (less than 3.5 mg/dL).

Finally, specific and specialized tests may be used to make a precise diagnosis of the cause of liver disease. Elevations in serum iron, the percent of iron saturated in blood, or the storage protein ferritin may indicate the presence of hemochromatosis, a liver disease associated with excess iron storage. In another disease involving abnormal metabolism of metals, Wilson's disease, there is an accumulation of copper in the liver, a deficiency of serum ceruloplasmin and excessive excretion of copper into the urine. Low levels of serum alpha1-antitrypsin may indicate the presence of lung and/or liver disease in children or adults with alpha1-antitrypsin deficiency.

A positive antemitochondrial antibody indicates the underlying condition of primary biliary cirrhosis. Striking elevations of serum globulin, another protein in blood, and the presence of antinuclear antibodies or antismooth muscle antibodies are clues to the diagnosis of autoimmune chronic hepatitis. Finally, there are specific blood tests that allow the precise diagnosis of hepatitis A, hepatitis B, hepatitis C, and hepatitis D.

In summary, blood tests are used to diagnose or monitor liver disease. They may be simply markers of disease (e.g. ALT, AST, alkaline phosphatase, and GGT), more true indicators of overall liver function (serum bilirubin, serum albumin, and prothrombin time) or specific tests that allow the diagnosis of an underlying cause of liver disease. Interpretation of these liver tests is a sophisticated process that your physician will utilize in the context of your medical history, physical examination, and other tests such as X-rays or other imaging studies of the liver.

Interpretation of these liver tests is a sophisticated process that your physician will utilize.....

Taken from www.hepatitis.org.uk

HIVandHEPATITIS.COM

Your questions answered.....

www.HIVandHepatitis.com have a page where patients can submit questions and receive answers from medical professionals. These are just a few of the recently posted submissions.

Question 1:
Could you e-mail me information about the adverse side effects of the peginterferon and ribavirin treatment in HIV/HCV patients? My husband is going to start treatment soon and I would like to know what to expect.

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

PEG-Intron (peginterferon alfa-2b) plus Rebetol (ribavirin), the only FDA-approved double combination treatment using a pegylated form of interferon, causes the same types of adverse events as Intron A (standard interferon-alfa 2b) plus Rebetol, but some occur more often. Adverse events reported in the clinical trials include flu-like symptoms (headache, fever, muscle aches), psychiatric disorders (depression, suicidal thoughts), and decreases in red blood cells, (which deliver oxygen to the body), white blood cells (which help fight infection), and platelets (which help stop bleeding).

Rebetol may cause birth defects or the death of an unborn child. You must not become pregnant while you or your partner are taking combination treatment with Peg-Intron/Rebetol.

Patients taking either of these two treatments should be carefully monitored by an experienced physician, get regular blood tests to check for adverse side effects and to see if the treatment is working.

Question 2:
I would like to know if there has been any comparison between Schering's Peg-Intron with Rebetol and Roche's Pegasys with Rebetol in regards to effectiveness and severity of side effects. I am scheduled to start therapy with Schering's Peg/Rebetol combo shortly but would be willing to wait for Pegasys/Rebetol combo if it's proven to be better. I have been diagnosed with genotype 2b and a biopsy showing grade 2 phase 1 fibrosis. Please advise.

Answer by Brian Boyle, MD
Dr. Boyle is an attending physician at the New York Presbyterian Hospital-Cornell Medical Center and Assistant Professor of Medicine in the Department of International Medicine and Infectious Diseases at Weill Medical College of Cornell University

Thus far, there has been no direct comparison between PEG-Intron (pegylated interferon-alfa 2b) and Pegasys (pegylated interferon-alfa 2a). At this point, the two products do not appear very different regarding effectiveness, safety or tolerability.

Question 3:
I am a haemophiliac living in the UK {United Kingdom]. I have HIV, Hep B and Hep C, (genotype 1a).I have been advised to go on the peginterferon alfa-2b and ribavirin [therapy]. Can you tell me what the percentage of success is and what side affects I may get.

Answer by Brian Boyle, MD
Dr. Boyle is an attending physician at the New York Presbyterian Hospital-Cornell Medical Center and Assistant Professor of Medicine in the Department of International Medicine and Infectious Diseases at Weill Medical College of Cornell University

Unfortunately, you have one of the genotypes that is hardest treat. The chance for success is going to depend on some factors you don't mention, like your CD4+ T cell count and your HCV RNA level. If your immune system is relatively intact (say a CD4+ T cell count of at least 300 or so), your chance of a sustained virologic response is probably pretty close to the non-HIV infected patients, i.e., in the 40-50% range. You should be able to evaluate your chance for success after 12 weeks of pegylated interferon/ribavirin therapy: If your HCV RNA is not undetectable or has not declined by 2 logs (about 99%) by 12 weeks, your chance of success is about 3% and it is generally thought that treatment should be discontinued.

Question 4:
I was diagnosed with chronic hep C last year and put on the combination therapy (interferon/ribivarin). I was able to last 7 1/2 months on it before I became so anemic that they took me off. I tested non-reactive to the virus at that time. They continue to monitor my viral load, usually in 4 to 6 month increments. What I would like to know is if I remain non-reactive, how long do I have to stay that way in order to be declared cured of the virus?

Answer by Douglas T. Dieterich, MD, FACP
Dr. Dieterich is Chief of Gastroenterology and Hepatology Cabrini Medical Center Assoc. Prof. of Medicine NYU School of Medicine

In general if the HCV PCR is negative 6 months after stopping, the chances of a relapse are less than 1%. If it is negative 12 months, less than .5%, and unheard of after 18 months. You can be pretty safe to use the "C" word after 6 months. Congratulations!

Question 5:
"I start the PEG-Intron [peginterferon alfa-2b] and Rebetol [ribavirin] on Monday. I think I remember in one of your weekly e-mails that [there is] a drug that will help keep a person from becoming anemic. If so, would you please let me know the name and the company that makes it?"

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

The drug you are referring to is epoietin alfa (brand names Procrit or Epogen). Procrit is manufactured by Ortho Biotech and Epogen is manufactured by Amgen. Epoetin alfa is a recombinant version of a human protein that stimulates the production of red blood cells and is used in the treatment of anemia associated with chronic renal (kidney) failure for patients on dialysis. It also shows promise in relieving the anemia associated with Rebetol (ribavirin)].

Question 6:
What are the four stages of severity for hepatitis C?

Answer by Douglas Dieterich, MD
Dr. Dieterich is Chief of Gastroenterology and Hepatology Cabrini Medical Center Assoc. Prof. of Medicine NYU School of Medicine

You probably mean the grades of fibrosis on liver biopsy. Generally cirrhosis is the most severe and is graded a "4." Transition to cirrhosis is a "3." Moderate fibrosis is "2" and mild is "1." It helps to grade the fibrosis to give us an idea about how long it will take until cirrhosis. Grade 3 takes about 2 years, grade 2 about 7 years, and grade 1 about 12 years.

Question 7:
I am a 34 yr. old haemophiliac with HIV/HCV. My HCV genotype is 3a. I completed a 24-week course of Peg-Intron and ribavirin (800mg/day) in mid-September. My HCV viral load dropped from over 1,000,000 copies to undetectable during the therapy. But now my HCV viral load is back to over 1,000,000 copies again.

My dosage of the PEG-Intron was only half of what I should have been taking at the beginning because my Dr. did not think I could handle the full dose. I gradually increased my dosage, and was finally at full dosage for the last month of therapy. Do you think I would still have a fair chance of achieving a sustained response if my dosage was at full strength for the entire 24 weeks?

Answer by Brian Boyle, MD
Dr. Boyle is an attending physician at the New York Presbyterian Hospital-Cornell Medical Center and Assistant Professor of Medicine in the Department of International Medicine and Infectious Diseases at Weill Medical College of Cornell University

Yes. studies indicate that you stand a significant chance of a sustained virologic response on re-treatment if you optimise the doses of PEG-Intron and ribavirin. Also, given your relapse after 24 weeks of therapy, you should consider lengthening the treatment period to 48 weeks. Good luck!

If anyone has any question they would like answered please visit http://www.HIVandHepatitis.com/doctor/main.html for recent questions and answers and e-mail address for your own questions

LONDON MARCH

The Manor House Group will be once again planning a march on parliament, which is due to take place on the 14th of May this year. They will be meeting in Trafalgar Square at around 12 noon and then marching on the Department of Health followed by the House of Commons. They will also be delivering letters to No 10 Downing Street on the day.

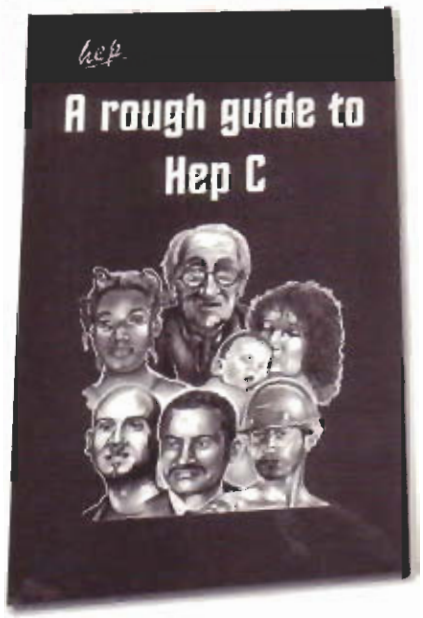
As we already know events such as these can only be successful if we all join together and act as one so I hope as many of you in the Haemophilia community will make the effort to attend.

For further details contact :

The Manor House Group
273 Chester Road
Grappenhall
Warrington
WA4 2QE

E-MAIL : manor@dircon.co.uk

A ROUGH GUIDE TO HEP C



is now out and is available from:

How's That Publishing
Eton House
156 High Street
Ruislip
Middlesex HA4 8LJ

Telephone No : 01895 637878

Or can be obtained through the Terrence Higgins Trust
Telephone No: 020 7242 1010
and Babs Evans at the Haemophilia Society

Is Hepatitis C (HCV) sexually transmitted?

There is no easy answer to this one. I have been to conferences where I have beard eminent physicians state categorically that HCV is not sexually transmitted, however amongst people co-infeeted with HIV the picture may be different. Widely discrepant findings concerning the sexual transmission of HCV have been reported in various journals and the first-generation of HCV tests did not identify all patients who were infected.

A recently published Italian study (1) aimed to assess the role of HIV infection in the sexual transmission of HCV. The prevalence of HCV in people with hetero- or homosexual contact who had no history of intravenous drug use or blood transfusion was evaluated according to the presence or absence of HIV infection.

106 HIV+ people (61 men and 45 women) attending an HIV day care clinic from 1994 to 1999 were studied along with a control group of 212 HIV- people (122 men and 90 women). Only those exposed to 'unsafe homosexual or heterosexual activity' were enrolled and this was defined as having had unsafe sexual intercourse with at least three partners in the preceding year.

All heterosexual participants reported vaginal intercourse and all homosexual participants reported anal and oral intercourse. The presence of HCV was higher in those with HIV than in the control group (15.1% compared to 2.4%). The prevalence of HCV infection was high in men who reported unsafe homosexual intercourse, regardless of HIV.

The study concluded that sexual transmission of HCV is rare in the general population, but that HIV plays a helper role in the sexual transmission of HCV, probably as a result of immunodepression favouring HCV replication.

Babs Evans
HIV/HCV Worker

1. *Filippini P, Coppola N, Scolastico C, et al. Does HIV Infection favor the Sexual Transmission of Hepatitis C? Sexually Transmitted Diseases 2001; 725-729*

Birchgrove Opinion
Although this study has taken a group of people who have no history of intravenous drug use or blood transfusions, it does not state whether they had any other recreational drug habits. Some data suggests that HCV can be easily transmitted through sharing a rolled up bank note to snort cocaine or amphetamines as the membranes in the nose are weak and easily bleed. It doesn't also state whether these control groups had tattoos or body piercing which can be routes of HCV infection. As the report shows HCV infection was high in men who reported unsafe homosexual intercourse. Could there be any correlation between this group and tattooed, body pierced cocaine users? Also there is no information regarding the heterosexual group's practising of anal sex. So still no clearer as to is HCV sexually transmissible?

I have heard eminent physicians state categorically that HCV is not sexually transmitted....

Side effects

INTERFERON
The most common serious side effect is depression, particularly in patients with a prior history. Most patients will have muscle aches, fatigue and low grade fevers. Nausea and diarrhoea are common as is irritation of the skin at the injection site.

Patients may experience significant weight loss, and if this occurs the dose should be adjusted. Patients often complain of irritability and headaches. A small number of patients may develop thyroid disease.

Normal thyroid function should be documented prior to treatment. Hair loss is not uncommon, but usually reversible. Few side effects are severe or persist after treatment.

RIBAVIRIN
The most common adverse experiences associated with Rebetron therapy are "flu-like" symptoms commonly associated with the use of interferon alfa. These include headache, fatigue, myalgia, and fever. These symptoms often decrease in severity as the time of treatment continues. However, psychiatric disorders have been reported during Rebetron therapy, both in patients with a previous psychiatric history and in patients with no history. These disorders include depression, which may be severe, and rare cases of suicidal thoughts.

Use of Ribavirin capsules can reduce the number of red blood cells to abnormally low levels in the body (anaemia). Red blood cells are necessary for carrying the oxygen in the blood to body tissues. As a result, use of Ribavirin may cause mild or moderate anaemia, a condition that lessens an individual's ability to use oxygen and makes them feel tired. For their patients using Ribavirin, physicians will measure the haemoglobin level in their blood while they are receiving treatment. Haemoglobin is a part of the red blood cells that helps to carry oxygen to the tissues.

Anaemia associated with Ribavirin therapy may exacerbate symptoms of coronary disease or deteriorate cardiac function. It is advised that complete blood count (CBC) be obtained just prior to starting therapy with Ribavirin, and after weeks 2 and 4 of therapy, or more frequently if clinically indicated.

Taken from HIVandHepatitis.com

# of Treatment

Interferon refreshes the parts...

When I was first asked to write an article for this Hep C issue, I was not really sure if anyone would be interested in my story. After much deliberation I was persuaded that it would be of interest, especially with the new pegelated Interferon / riboviran trial going on at this moment in time. I had to trawl through my old diaries to come up with the dates for this article, and to be honest I was surprised to discover how long ago it actually was when I started on interferon, Wednesday 10th November 1993 to be exact.

I had visited my Haemophilia Centre about three weeks previous to this and they had suggested an appointment with a Hepatologist. I agreed and within a week I had an appointment. He asked me would I be interested in a trial involving three injections a week of the drug interferon. We chatted for a while, he showed me a video of how to inject myself and after half an hour I had agreed to take part.

Thinking back I didn't really take enough time over my decision, but that was then and this is now. So, as I said I started on the 10 November '93 and took my first shot that afternoon. I spent the next 48 hours travelling between my home and the hospital having my blood taken. Everything was OK, so I decided to go out for a few beers that weekend. To say it was a mistake would be an understatement, after a few hours I started to get the shakes and sweats, so I went home to bed. I stayed there for a day or two until I was ready for my next jab. This time I took it and stayed in the confines of my own home. Luckily enough I didn't have much of a reaction this time, just a mild headache. I didn't have a drink for the next few weeks just in case I had another bad reaction, but Christmas was on its way and the party season was in full swing. It was late December and I had been out a few times, but had resisted the temptation of a few beers.

...other drugs cannot reach.

One night I thought sod it and decided to try just the one, and just the one it was. I don't really know why, but it tasted disgusting !!!!!!!! It left an awful metallic taste in my mouth and a few days later I had a mouth full of ulcers. I thought that was it, my drinking days are over. How wrong was I?????? Christmas came and left and on we went into 1994, the year I discovered the black stuff GUINNESS.

It was like discovering alcohol all over again, and it liked me, no bad taste in my mouth just a lovely yummy feeling inside. It was like alcoholic Ready Brek. On I went all through the early spring and summer, but things were not good, I started to skip injections and would then end up having to jab myself every day to catch up, sometimes I would even take all three weekly jabs in one go. I was drinking copious amounts and really started to lose the plot. I had come to a point where I was injecting myself every day, if it wasn't the interferon it was my Factor VIII. Yet every time I went to the hospital they would tell me that everything was OK, all my test results were excellent and I had become PCR negative. So I just continued with the life style that I had gotten used to, head down, bollock on and fuck what everybody else thought. Summer turned to Autumn and the end of my trial loomed closer and closer. Wednesday 9th November 1994 I took my last injection. I was so happy to be finishing the bloody trial that I didn't really speak to the hospital for quite a few weeks after I had finished.

...after they had collected all the data, and informed me that it had been a 100% success. I was pleasantly surprised, as I had done everything wrong during my year on interferon.

They gave me a ring, after they had collected all the data, and informed me that it had been a 100% success. I was pleasantly surprised, as I had done everything wrong during my year on interferon. Was I lucky? Yes I probably was. I know of other people who stuck to their regime religiously, and their levels were no different at the end of the trial. It was about this time that I joined Birchgrove Wales, and after many a long chat I realised that I was a very lucky bunny indeed. If I had met the Birchgrove Wales lads a year earlier would it have made a difference to the way I lived the previous year? Probably yes, but would I have been PCR negative at the end? Who knows.

Eight years on and everything is still OK. All the friends I have made over these past eight years, through Birchgrove, have been a constant source of support. To all of you who have recently started the interferon / ribovarin trial I wish you luck and hope that at the end of it we all have something to celebrate, soft drinks only.

Martin

Mainliners 6th International Hepatitis C Conference

Lisbon Portugal 7th & 8th February 2002

I am about to start my own treatment for HCV very soon so I had an agenda to find out as much as I could during this conference as well as participating in a workshop. Having attended the last Mainliners Hepatitis C conference I thought I had a good idea of what to expect and I wasn't disappointed as the event was an excellent opportunity to hear expert speakers from around the world talking about diverse issues concerning Hepatitis C. This conference was organised by The National Hepatitis C Resource Centre in conjunction with Abraco, A Portugese sexual health organisation and the British Liver Trust.

The diversity of the delegates attending gave a wealth of knowledge, which as ever was disseminated over breakfast, lunch and dinner and into the early hours of the morning in the hotel bar, (even if a number of those were drinking orange juice or soda water). The issues raised around HCV were very similar to those of HIV and nearly every speaker throughout the conference spoke about HIV or HCV in the context of HIV and Co-infection at some point.

The conference started by addressing the issues of education, trends and attitudes in relation to Hepatitis C. This was highlighted by the fact that couriers collecting resource material to take from the National Hepatitis C Resource Centre to Lisbon initially refused to take the boxes when they saw that they were labeled with Hepatitis C.

The first of the speakers was Dr Harold Margolis who is head of the Hepatitis Branch from Centre for Disease Control, Atlanta, Georgia, USA. (hsm1@cdc.gov). Dr Margolis talked about the global threat of HCV with its 176 million infections worldwide. Global figures were alarming and obviously growing with countries such as Italy, Japan, Spain, Ireland, USA, all having high incidences, with Egypt topping the lot. Unsafe medical practices were blamed as a major contributing medium for transmitting HCV including blood transfusions and blood product use. Interesting to note that the highest rise of HCV incidence of infection in the USA was between 1975 and 1989 at a time when blood was used widely to produce Factor 8 without any screening.

To implement an effective prevention programme Dr Margolis argued that HCV should be used as the indicator as there were strong reasons to combine HCV with HIV, STD'S and IVDU's within a national programme. As resources and strategies have been set up for existing HIV and STD programmes it was rational to include HCV prevention and treatment into these in the future. It all made sense to me. Dr Margolis raised the issue of reduction in paid donors to reduce the risks of infection. As the blood product I use is made from remunerated US donors I thought I would ask him to clarify a few points about this after his talk over coffee. He assured me he was referring to developing countries such as China where blood sale was rife, and that carefully monitored regular screened paid donors in the US, whose blood was used for products that were then virally inactivated and heat treated posed little risk, but of course not an absolute guarantee as we know.

Mauro Guarinieri, based in Italy, from the European Aids Treatment Group (mauro@eatg.org) spoke about European current hepatitis C policy and came from a co-infected perspective reiterating the fact that HCV and end stage liver disease is now the leading cause of mortality in co-infected cohorts. Issues around the toxicity of the treatments available, the severity of side effects, denial of treatment to individuals, hepatoxicity interactions and the lack of access to transplant organs were all raised. Mauro stressed that we should learn lessons from HIV and involve the patient to refine research and enhance prevention programmes, policy and treatment so that future treatment is more efficacious and tolerable.

The Political Dimension was discussed by Jon Derricott and was based on the work of Action on Hepatitis C and the UK Harm Reduction Alliance. The attitudes of the Government towards HCV, discrimination, political budgets, unrealistic policies, society perception and respect for human dignity were all raised in the context of IVDU's and the wider world of HCV infected individuals.

HCV in injecting drug users was presented by Lucas Weissing an Epidemiologist from Portugal, which was overloaded with graphs depicting infection rates across the globe. He focused on the epidemiology, prevention, treatment and what we need to know and what we need to do in the future to combat HCV infection.

After lunch Brian Edlin from IHPS,U.C. San Francisco USA, presented a talk on treating Hepatitis C in injecting drug users and overcoming the social and cultural barriers to provide care to marginalized patients. This addressed issues such as the social intolerance and punitive measures that are imposed on drug users and how it inhibits the perception of them as a patient and an individual needing medical care rather than incarceration and rejection. He advocated that in managing effective health care we should establish a climate of mutual respect, avoid moralizing, blaming and judging and that we educate patients and include them in decision-making.

Jerome Weinbach (j.weinbach@lume.nl), from HCV Cluster CDC Netherlands gave for me the most enlightening talk of the conference about Current Hepatitis C research and the future. He discussed the issues of current treatment of Pegylated Interferon and Ribavarin as the gold standard of care but highlighted that at best it was only a therapeutic option and not a panacea. He explored contra indications to treatment success, poor response rates, especially with genotype 1 and older patients. The toxicity of the treatment, compliance problems and the cost effectiveness of treating HCV were all themes of his presentation. Then came the bit I was interested in. Is there any hope for the future that treatments will get better and improve so that they are not so toxic, so that they can be tolerated easier with better prognosis? Well the good news is that there are a lot more options than I expected or thought existed, but the bad news is that they are all in experimental stage and may be several years before they are thoroughly tested and on the hospital shelves, if in fact they make it that far. Most of them are variations on Interferon and Ribovarin and some are on trial in some parts of the world.

Other studies are also taking place to help identify drug resistant mutations and HCV replication, but the bottom line is that the future is very uncertain as funding for this research is in decline. Jerome is asking for your support to sign the EU Hepatitis C Petition to lobby and try and secure financial support for Hepatitis C research in Europe. Jerome asked for anybody who wants to help this cause to please contact him at his above email address for further information.

After a much needed coffee break Nigel Hughes of the British Liver Trust presented "A Decade on-What have we Learned and where next?" which opened up a lot of interesting debatable topics. The incidence of HCV is increasing at an estimated 2 million people newly infected each year through contaminated blood products, whole blood and inadequately sterilised medical procedures. There has been a reliable test available since 1991, Japan started screening blood in 1989, Belgium in 1990 and the UK was the last country in Europe to introduce blood screening in September 1991. Although treatments are available now there were only 1260 patients treated for HCV in the UK last year out of a minimum estimate of 250,000 infected patients. So how do we try to reduce

Is there any hope for the future that treatments will get better and improve so that they are not so toxic?

There was emphasis put on the fact that HCV infected individuals need a greater understanding in order to make decisions that affect their lifestyle.

transmission if we are not putting enough resources into attempting to eradicate the virus from infected individuals? The same kind of irrational thinking was also illustrated when Nigel explained that 8% of the UK prison population is infected with Hepatitis B (7% with HCV) and yet although we have had a vaccine for HBV for some years it has not been implemented in the UK. Just by offering inmates a hepatitis B vaccination during their initiation would drastically reduce this infection rate and also stop it being spread into the population at large on their release. The same kind of insane rational is employed with regard to needle exchange and condom availability in prisons. Society believes that drug use and sex shouldn't and doesn't happen in prisons so they are not available.

There was emphasis put on the fact that HCV infected individuals need a greater understanding in order to make decisions that affect their lifestyle. Hepatitis C can reduce the quality of a person's life via their general health, vitality and mental health. The issues of co-infection were that HIV alters the natural history of HCV, as there is an increased morbidity and mortality, the clinical management is more complicated and the cost of therapy increases. The burden of HCV is enormous and yet there seems to be little progress.

At this point I needed to recuperate in the bar and unfortunately missed the abstract presentations, which concluded day one of the conference.

Day two consisted of workshops, which were a welcome relief after the heavy content of the first day. I attended the Treatment workshops "What are the best current indications for treatment?" and "What constitutes current standard of care". Dr George Bird started off by stating that the worst prognosis is found in HIV co-infected, Genotype 1, and males over 50 who drink and smoke. This was a cheery start to the morning as I fitted into all those categories except age. Dr Bird spoke about patient choice and acceptability of the treatment by the patient as well as treating the virus in all of its stages of infection. The aims of HCV therapy are to eradicate the virus and decrease the chances of liver cancer so patients with cirrhosis should be given the same access to HCV therapy as non-cirrhosis patients. This thinking gives even less of an argument for pre treatment biopsies as an indicator for treatment especially in the Haemophilia population where bleeding is a concern.

Will Rosenburg, consultant hepatologist, echoed the same sentiments in his part of the workshop and advocated the use of pegylated Interferon as opposed to non-pegylated and also the importance of the medical team. Who delivers the treatment and who supports the patient was addressed by it being nurse led and consultant managed with ancillary services in place. It was stressed that HIV /HCV co-infected should be very carefully monitored by a specialist team and not just added to a cohort of HCV mono-infected patients.

Nigel Hughes and Robert James had a double act Professional vs. Patient in the "best way to manage therapy" workshop where Nigel gave medical opinions and protocols and NICE guidelines and Robert illustrated what they meant in reality to the patient. Issues covered were the health care delivery, adherence and motivation. When treatment failure is discussed is it the patient that fails, the treatment or the system? Why do appointments suit the doctor and not the patient? Are guidelines only for crap doctors and lazy patients? This was a refreshing look at the medic / patient relationship and summarised with a need for medics to listen to and embrace the experience of patients.

Will Rosenburg concluded the morning session that I attended with "What are the primary endpoints of therapy" which focused on achieving a sustained viral response. If the patient is PCR negative 24 weeks after the end of therapy then this is as close to a cure that we can measure at present. Nobody knows whether the virus will re-appear in the future. He discussed the use of long term, low dose interferon on SVR non-responder patients, as there is some evidence that although it will not eradicate the virus it may reduce liver cancer, which is something to consider if the treatment has been unsuccessful already. It was pointed out that during the treatment of HCV it is a very vulnerable time for the patient and they need as much support as possible. There was a quick round up of what adverse side effects could be expected including fatigue, flu-symptoms, mood disturbances, depression, aggression, weight loss, skin rash, hair loss, libido loss, breathlessness, fetal damage and thyroid disturbance. All topped off with the fact that some of these symptoms may still occur after treatment has ceased, in particular, thyroid problems, depression and hair loss in older men.

After a delicious lunch and desert of pasteis de nata (custard cakes to you) the afternoons workshop I attended was by the Haemophilia Society on "Successful lessons learned from campaigning" where Chris Hodgson talked about the Societies' carpet of lilies campaign, the All Party Parliamentary Group formation, and issues in the UK news such as last years HCV payments to blood product recipients and the unjust system that we face. He concluded by showing the last 10 minutes of the Meridian TV documentary "Blood Brothers" filmed last year. This had a dramatic effect and some delegates actually admitted that they were holding back the tears. Overall it did provoke a response as some people were of the belief that we had already had a public inquiry.

The last workshop of the conference was run by Robert James and myself on "Long term survival and coping with HIV and HCV " from a patients perspective. I did a short presentation on the complexities of living with 2 deadly viruses and a long-term medical condition and then we presented 2 case studies that Robert had devised. The point of the exercise was to identify the obstacles that we face when accessing medical care and how we as patients can become involved to have a say, so that medical intervention is designed for the person and not the individual viruses. Comments made where that for each question raised more questions were generated not answers, so I think we made our point.

The conference was concluded with a summary and I am glad to say that after such depressing subject matter and information overload the conference ended on an upbeat note. The role of patients was seen as important at all levels, accountability and an inquiry into all contaminated blood products, the need for multidisciplinary specialists, high quality effective prevention measures were advocated and most importantly the need for an established framework for co-ordinated application of pressure, to build alliances with all HCV groups and advocate for good practice.

The following day was spent recovering in bed and then off to sit in the sunshine outside cafes eating more pasteis de nata, cold beers, (while I still can) and a bit of sight seeing around the old back streets of Alfalma and St Jorges Castle. It was necessary after the two hectic days of hepatitis C overload.

All the abstracts and presentations should soon be available on the National Hepatitis C Resource Centre web site www.hep-ccentre.com and also available as a CD-ROM, or email advice&info@hep-ccentre.com or contact Mainliners at linersmain@aol.com for further information about this conference or other future events.

DAMAGE LIMITATION

Which Road.... Hepatitis Infection?

Any journey we take in life, we hope, will be a pleasant one as most, and fortunately are. Especially if the journey we take is well prepared and we are sure we have picked the right route. As I am sure you will appreciate, therefore, the little unknown world of Interferon treatment for the co-infected haemophilia was a journey I did not embark upon lightly! However, it was a journey, which I am grateful I was offered and able to make.

My powers of reasoning were constantly being challenged and it was a battle to decide whether my enlarged and grumpy liver was the result of the HCV or taking my recommended dose of fodder for my HIV condition. As the tenth anniversary of starting treatment with AZT – progressing to my current triple combination of Lamivudne, Nelfinavir and Abacavir - approached, I had many things to consider. My ALT levels were continually high and the doctors had no way of telling me which of the two viral infections were to blame. It was a juggling act but it seemed that the best route would be to clear my HCV infection out of the bag of balls they put in front of me.

Having thrown the balls into the air, I then had to decide how to catch them when they came down! What time should I start to successfully complete the course in six months? Any additional (drug regimes) and their effect on my "Viral load" and CD4 levels, was a serious consideration. My viral load had been undetectable for more than a year and my CD4 had climbed to the dizzy heights of above 300 and remained stable for six months. This gave me room to manoeuvre if any results were moving in the wrong direction with my HIV treatment. The fact that I had noted any adverse effects, and learned to accept the side effects of my current drug regime, while still maintaining a reasonable quality of life, it gave the doctor and myself a baseline to note any changes with confidence.

Keeping a daily record, if you can, certainly helps, as does discussing progress with the doctor at monthly reviews. A good tip I found helpful was to give myself a daily rating on how I felt. Generally, a 1-10 scoring process is good but, if it is continually declining, don't let the trend proceed for longer than 5 days without speaking to your doctor.

Before starting HCV treatment, abstain from taking alcohol completely for at least two months. This may turn out to be the best and safest Hep C treatment you need! It will also prepare you for the time when you start Interferon. If you cannot comply with this small concession before or after, your chances of success will be greatly diminished. Once you have eliminated all avenues, and the doctor still advises you to begin treatment, then go for it! Don't forget to give yourself a goal to aim for after your treatment ends: whatever the outcome.

It's a big commitment to have a clear understanding of the road ahead so that you don't get lost! To comply with my prescription of Interferon (3 injections a week), Ribavirin (5 tablets daily) and Amantadine (2 tablets daily), plus my HIV regime, can get complicated.

Sort a routine that suits your individual lifestyle. Try and give yourself 30 minutes of peace after your injection. Write your diary. Relax if you can. I soon discovered that rushing about after the jab made the process of absorption a little quick and left me feeling flushed and a bit unsteady, vulnerable and not able to move about the house with confidence. It reminded me of the feeling you would get sometimes when you, or the doctor for that matter, gave cryoprecipitate quickly. With a (size 19) butterfly. It took me until the start of my third week before any consistency with the day and time of treatment settled; the main reasons being eating before injecting and sleeping if given too late at night. Monday, Wednesday and Friday, with the weekend off, worked for me.

Apart from some unavoidable interruptions due to dental problems, my normal daily routine would be:

7.00 am
Up and out with Sandy the dog.

8.00 am
Breakfast.

8.30 am
HIV treatment and then shower.

9.00 am
HCV treatment (Interferon-Ribavirin).

9.30 – 10.00 am
Haemophilia pain relief (Co-dydramol, Vioxx) and then quality time.

12.00 – 2.00 pm
Depending which suits, feeding time with any complementary therapy or supplement drugs, multi-vitamins, antibiotics and then a healthy snack – think Mediterranean.

2.00 – 6.00 pm
Quality period. Being self-full may play on your conscience but look on it as a self-mending time for your body. Even sleeping, when needed, has a constructive value to your well-being, especially if you are not sleeping well during the dark hours.

6.00 – 7.00 pm
A good balanced meal followed by HCV treatment (Ribavirin, Amantadine).

7.00 – 10.00 pm
Family time.

10.00 pm
Hot milk herbal sleeping potion with digestive biscuit followed by HIV treatment with News Night in bed to drift into Slumber-land.

By the eighth week, my Hep C (PCR) had gone negative, which seemed like a good reason to celebrate with a pint of Cranberry Juice. But, to be honest, my wife and I found the news hard to accept, with our emotions wanting to do one thing when our common sense would only allow us a few tears of relief. The first two months of HCV treatment had not passed without some major family commitments to help with my care and rational thinking. Concentration, chills

Having thrown the balls into the air, I then had to decide how to catch them when they came down!

DAMAGE LIMITATION (continued)

and a decrease in energy levels were the main reasons. There had been a reduction of my CD4 count (200) but my Viral Load had remained undetectable.

Three months into treatment came with a few comments of encouragement, as I had marked the kitchen calendar with days of injections and had been crossing them off as they were given. Reaching the halfway point had recharged my determination to complete the course. It had also been a good reference for the family and friends to note as they increased my need to rest more or go to bed to get warm. There had been a fall in my weight, due to my appetite, but mainly because of a dental infection. I found food more appetising in small amounts as a full tummy made the pain in my liver regions increase.

I developed a liking for sweet puddings, chocolate and food that gives you high energy levels for a short period of time. This also helped with the weight loss. Changing the area of injection site around the tummy to relieve tenderness also had a plus side. I ended up with a nice six-pack without any training involved. It helps if you can try to find a positive to every negative. However bad you may feel, it is important to keep the scales balanced while living with any long-term health condition. I can assure you that the people who love and care for you will be feeling worse. Read children's books, as they will make you laugh. Perhaps "It could be worse" by?

Things did improve as I passed the summit of my journey into Interferon world. It became a lot easier on the homeward leg. Downhill all the way to the finish line, being put back on my feet by my support team every time I fell down.

So, we came to the end of the road and took the last jab. Time out to evaluate whether it had been worth going or would it have been better staying at home? They tell me that the main end result of a negative HCV (PCR) test failed as, by the fourth week of stopping HCV treatment, I tested positive. This was a bit disappointing but not something we had not considered and prepared for. So we did not waste any time looking for reasons why or questioning starting treatment. There were many more positive things to concentrate on, like my Viral Load had remained undetectable and, on stopping, the Interferon had made my CD4 jump up to 500+. Let's hope they stay that way!

It had also made complying with just taking my HIV treatment easier and simple. A piece of cake almost! I hope that, whatever the medical team gained from studying all the tests completed during and after the treatment will be of great use to them when making future decisions about me and other patients in the same position.

It's strange but it reminds me of betting on a horse, which finishes second. You never mind losing your stake because you had studied the form and weighed up the odds. He had run a good race but was not quite right on the day. Take what you have learned forward to the next race, with a little more knowledge and confidence as to the outcome. After all, we are all different and what did not work for one may work for someone-else.

Take care.
Haydn
(printed with permission of Haemophilia Wales)

It's strange but it reminds me of betting on a horse, which finishes second.

BOB THE BLEEDER

Dear Bob, I have difficulty when I am on top of my girlfriend. My elbows are not strong enough to push myself up and down for very long. She is happy to go on top sometimes but does not want to do it all the time. Do you have any advice?
Yes, what you need is a way of taking your weight off your elbows whilst your on top. Have you tried the bondage gear available from all good sex shops (I find a good local hardware shop will often suffice). Attach this to the ceiling in your bedroom. These come with ropes in hemp, leather and plastic for your individual fetish needs and will allow you to be strapped in securely above your partner. Assuming you go for the top of the range model at the flick of a switch you can raise and lower your body thus saving your partner the bother of pulling the ropes in order to move you up and down. It is obviously more discrete if you can pay privately for this yourself but if you are short of a bob or two start by getting a referral to an OT, Occupational Therapist and explain to her your problems. They can liase with Social Services in order to identify the appropriate system of ropes, pulleys and electronics that you need. If Social Services cannot fund this attachment have the OT write a report for the MacFarlane Trust and ask them to fund it. Bearing in mind that it has to be for medical purposes remember to highlight the medical benefits of regular sex and the importance of pleasuring your partner. Sex is after a biological drive and needs to be acknowledged in any holistic approach to health.

Bob, the rendering is coming away from the front of my house, can you fix it?
No! What do you think I am, a builder??

Bob I have a problem when I am injecting. I always seem to get stiff just before I stick it in and I can't seem to avoid having some of the liquid dribble out of the end. This leaves a sticky residue and I am worried about losing the last few drops. How can I avoid this?
Simple put everything in a condom and before injecting into your vein. This is a "safer-injecting" technique and means that any dribbles will be caught by the condom which you should throw away into your yellow sharps box. (Remember it is inadvisable to re-sheath) To be absolutely certain you should also place a "Danger of Infection" sticker on the condom before you use it as you would before having intercourse. These can be got from any Pathology Laboratory at your local hospital where the staff are usually happy to distribute these labels to anyone coming into contact with the bodily fluids of someone with HIV or hepatitis.

Do you have a question for Bob the Bleeder? Please send it in and we will attempt to both answer it and fit it into the funding criteria of the MacFarlane Trust.

Bob the Bleeder would like to avoid any confusion with persons alive, dead or animated by stressing that he does not wear check shirts, boots and turn-up jeans. He is not a gay icon and does not sing pop songs. Furthermore he would like to stress that he was never in the village people as the 'construction worker', that is a vicious rumour put about by his agent.

can he fix it?

CAMPAIGN UPDATE

A government investigation has been launched into the "worst-ever NHS treatment disaster" after The Journal exposed the infection of thousands of haemophiliacs with hepatitis C. In an exclusive interview with The Journal earlier this year, former Labour health minister Lord Owen revealed how a commitment made by himself in 1973 for the UK to become self-sufficient in blood products was never achieved. He also told for the first time how documents relating to the bad blood debate had been "pulped", despite a rule that all official documentation must be kept for 30 years.

This failure to meet demand meant that for more than a decade, haemophiliacs were treated with imported clotting factors taken from high-risk paid donors in America and South Africa. As a result 4,500 developed hepatitis C and HIV and many have since died from their infections. In the North-East alone, 95 out of 105 became infected and just 18 remain alive.

The Department of Health has now agreed to re-examine all available documentation after copies of The Journal's Bad Blood Campaign was sent directly to Tony Blair by the president of the Haemophilia Society Lord Morris. In a letter from Philip Hunt on behalf of Mr Blair, the Health Minister says: "The Prime Minister has asked me to thank you for sending copies of the statements made by Lord Owen to the Journal about clotting factors for people with haemophilia. "The Department's officials are looking into the points raised and I will write to you again when the examination of all relevant documents is complete."

This is a major step for haemophiliacs who have been fighting for justice for almost a decade, ever since they were tested for hepatitis C in 1992. The Government has continued to refuse a public inquiry into the disaster, claiming the infection of haemophiliacs through NHS treatment was a "tragic accident". However, Lord Hunt admits that as early as 1970, clinicians knew there was a risk of hepatitis being spread and it was only because of the "enthusiasm" for the treatment from sufferers and their doctors that treatment was continued.

Carol Grayson, from Jesmond, whose partner Peter Longstaff was infected with both hepatitis C and HIV, said last night haemophiliacs had never been given all the facts to make an informed decision. "Fears over product safety were never mentioned to haemophilia and we have still not received answers to our many questions about how infected blood products were allowed into the country and who licensed them," she said.

"The fact that the Government has agreed to investigate Lord Owen's claims is an important step."

Lord Morris of Manchester added: "It is grossly damaging to the reputation of the NHS that we still await an inquiry into its worst treatment disaster. "Lord Owen claims that money laid aside in 1973 to protect haemophiliacs from infection through blood-borne viruses was diverted to other purposes. Surely this is further evidence of the need for a full and open public inquiry?"

The DoH confirmed that inquiries were underway.

'Worst-ever NHS disaster' Dec 5 2001 By The Journal

letters letters

Dear Robert,

I feel impelled to respond to your article in Birchgrove "Relationships". My God you young people! You are so impatient. In my experience it takes at least 50 years to find and form a good relationship. Hold you hard! *(Norfolk vernacular)* Just regard all relationships as temporary learning experiences, which will build to a perfect climax in your later years. *(Believe me these come really good).* So get your finger out and keep your hand in, practice constantly, maintaining yourself in readiness for that perfect relationship.

First of all you need a better opinion of yourself to enter next time in 'Soulmates'. Define things more closely as in: -

Honest: knows how to work the system legally
Unemployed: I do not need employers - they need me.
Cripple: nonsense, one arm almost works, 2 moving legs.
Defective genes: it's not your fault that you have one genetically careless parent
Poisonous sperm: no, not all of them. Have a little pity, all bar one of these million guys die before ever forming a relationship
Learn to think positively even if you are now only nearly HIV+

You must realise that everybody has bits that do not work - for most people it is their brains. Not wishing to boast, I bet I have more bits missiug than you've had hot dinners. Tony was in a lousy relationship for years but he never stopped hoping and practicing and now I can rely on his strong right arm to open all my jars.

As a family, we set a very high standard for partners. Personally I demand a high intellectual capacity for washing up and a dust tolerance of about a quarter of an inch. But if after all you really feel you are crap at relationships - make friends with your computer. You are at least interacting in a binary way.

The Speaking Chair

Well, my article in the last one seems to have hit the spot. We even received letters about it, including one from my mum! No overprotective haemophilia mothers syndrome there I think you can tell. Perhaps we should talk about sex more often or would Birchgrove end up like cosmopolitan. Perhaps we should rename the magazine BQ or Bleeding Quarterly *(That's a stupid name - Ed)*. Please keep writing, as it means we have less to do for the magazine and doing less is the committees New Year Resolution!

Birchgrove is in conference season, at the moment with Mainliners Hepatitis C in Lisbon. The Haemophilia Alliance at the NEC *(Not quite Limp Bizkit but I'm sure they rock)* and later this summer the World Federation of Haemophilia in Seville. One or more of us may also appear with Babs in a series of evenings about HIV/HCV co-infection around the country. So if the thought of travel appeals to any of you and honestly who could resist the idea of discussing Haemophilia Service Specifications on a cold February day half-way between Birmingham and Coventry, get in touch. Usually we have to do things in order to get to these conferences *(it means someone else pays for your planes, trains and automobiles to get you there)*, such as write it up for a magazine or run a workshop, but it can mean a free holiday in Lisbon. And let's face Portugal has got to be warmer, dryer and less windy than here at the moment.

Robert

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@haemophilia.org.uk
Hepatitis 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@hep-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@akitanet.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
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

Campaigning Groups

Action on hepatitis C (AHC)
Formed by professionals and service users out of concern at the lack of national progress in tackling the hepatitis C epicemic.
Website: http://ahcuk.50megs.com/index.html

Haemophilia Action UK
PO Box 782
Newcastle Upon Tyne
NE99 2UW
E-Mail : kunming@ukonline.co.uk
Website: http://web.ukonline.co.uk/kunming/

Manor House Group
Self help support and campaign group for people with haemophilia and HCV
Chair 01384-457515
www.manor.dircon.co.uk/

Its been quite a few years since the last Hep C issue was written and not only the treatment but knowledge about it has changed quite a lot since then. When the steering group sat down at our last meeting one of the items on the agenda was thinking of new and exciting ideas and topics for the newsletter. Although we did come up with some new ideas as I hope you have seen in previous issues and future ones, we all agreed that a lot of the old topics covered in old issues such as Hepatitis C and Drugs needed revisiting as issues and information have changed so much over the years.

It also appeared that a lot of people I have spoken to are just finishing, just starting or trying to decide about going on treatment for their Hepatitis C. Out of the six Birchgrove steering group, two of us have recently started treatment (myself and the chair), one is looking to start in April and another had treatment many years ago and was cured (touch wood). As a consequence of this we have been surfing the net, reading medical books and chatting to as many people as we can to enable us to make an informed decision on what would be best for us, whether to treat or not, what are the treatment options, what are the chances of it actually working and what the bloody hell is this genotype everybody keeps on about.

So in this issue we have endeavoured to put together as much information as possible, from treatment updates to personal stories hoping that you will go away feeling well informed, and not like most of the medical bumf I have read that makes you fell like running down the road shouting "my head is about to implode".

Birchgrove is a platform for its readers to contribute and express their views and this is why we endeavour to give up to date information alongside personal stories. Regardless of were the funds for the newsletter come from Birchgrove will never be influenced as to what the content will be, and I feel because of this it will always remain a voice for our members. With this in mind that is why you as a reader should put pen to paper and let us now how you feel whether in our letters page or something for our next issue about DRUGS, this can be from HIv/HCv, Painkillers or recreational drugs.

We as a newsletter are here to give advice and support in any way we can and you require, but to do this we need your input, ideas and thoughts to survive.

PLEASE NOTE THE NEW TELEPHONE NUMBER IS 01473 429552

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 inn fear and isolation.

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

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.

"BIRCHGROVE" is published by Birchgrove Group.

P.O.Box 9755
Solihull
B92 9WA
E-mail: birchgrove1@hotmail.com
Tel: 01473 429552

The Birchgrove newsletter is funded by the haemophilia society