Hepchat
A newsletter bringing up to date information for HCV patients by HCV patients.

Hepatitis C web sites;

www. hepcscotland.org.uk

www.hivandhepc.com

www.hepcuk.info

www.hepnet.com

www.britishlivertrust.co.uk

Phone: 07989 532317
Email: info@healhep.com
or
Write to: H.E.A.L
'The Surgery'
32 Lauriston Place
Edinburgh

Raising Awareness

(Taken from Hep C Trust web site)

The media are always looking for case studies of people who have hepatitis c.
They at e more likely to do a feature if they can include a real story.
If you are able to speak with the media then call Jane at the Hep C Trust 020 7089 6220 and she will explain what is involved.

Go On Call Today!

We're
On The Web
http://www.healhep.com

H.E.A.L's Dragon logo designed by: dollydoes@hotmail.com

News on HCV

Dec 1st 2003 saw the launch of the new Scottish Hepatitis C Centre based in Glasgow. Their aims are;

To develop a central information centre for patients and professionals seeking factual information or local information relating to Hepatitis C in Scotland

To encourage collaborations and cross sector involvement in Scotland that may improve services for patients and/or professionals in relation to Hepatitis C.

To facilitate an awareness and understanding of Hepatitis C in Scotland

Visit their web site http://www.hepcscotland.org.uk

Support Groups and Help Lines

H.E.A.L 07989 532317
Edinburgh
Newsletter, info, advice, self-help, support, and chat line.

Capital C 0131 478 7929
Edinburgh
Info, advice, Support group meets monthly.

C~Level 0141 332 2520
Glasgow
Support group, info ,advice, .alt. therapies, testing

Positive Friends 0141 954 2451
Glasgow
Support group, info, advice.

British liver trust 0808 800 1000
Info, advice.

Mainliners 020 7582 3338
London
Support group, info, advice.

The Haemophilia society 020 7380 0600
Support group, advocacy, info, advice.

Hep C Trust 020 7089 6220
London 0870 200 1 200
Help Line
Weekdays 12 p.m—6 p. m (thurs 7 p.m)

The information in this newsletter is not intended to be used as medical instruction.
Your G.P. should be consulted before taking any action based on any of this information.

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Hepchat

Hepatitis C information for patients by patients

Welcome

In April 2001 H.E.A.L received funding to produce the Hepchat newsletter along with informative leaflets on issues around Hepatitis C. The editing team would like to thank the Millennium Award Scheme for making this possible. Hepatitis Education & Awareness Lothian have been in existence since 1999, our aim is to provide current up to date information regarding the Hepatitis C Virus. We operate a help line for information, advice, support or just a chat, which is completely confidential.

If you have any questions, no matter how stupid they may seem, then please ask, as there are no stupid questions when it comes to this virus. There is not enough information regarding it available. If you, a friend or family member are affected by HCV then why not call, write or email. We would like to hear from anyone with a story to tell or any questions needing answered or anyone wishing to contribute to our newsletter for future issues please do so.

Hepatitis C: A Brief History

The Hepatitis C virus was identified in 1989 and testing became available in 1990. Many people either previously diagnosed as non-A non-B or post-transfusion hepatitis were retested (or their stored serum was tested) and were found to be hepatitis c positive. Hepatitis is the general name for several different illnesses that all cause the same problem, an inflamed (swollen or painful) liver. The liver is a vital part of the body, if it does not function properly it can cause serious illness, sometimes even death. Drinking alcohol or taking drugs can also cause hepatitis. It can also be caused by a viral infection. There are several types of hepatitis ranging from A—G. It is now recognised that Hepatitis C is one of the most common types of hepatitis with up to 1.5% of the population being positive.

Basic Research is Limited

It is very unfortunate but there is no good animal model for hepatitis c and the virus has not been grown in tissue culture. This means that basic studies on animals of the virus are not possible and studies are limited to gene sequencing and clinical studies. This fact is one of the reasons a vaccine is very difficult to develop.

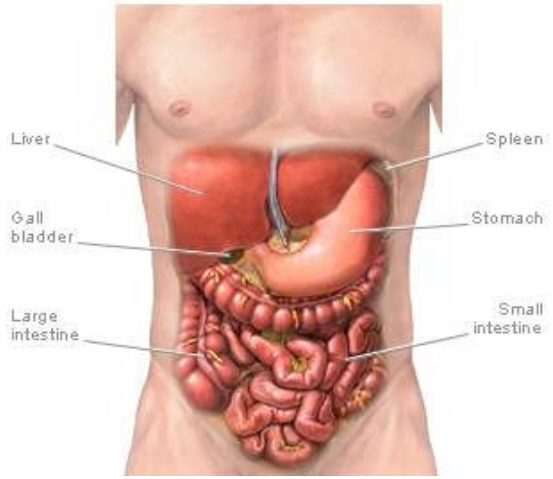
Many Types and Subtypes

The Hepatitis C virus is not one single virus, there are differences in the gene sequence resulting in 6 major genotypes. Within each genotype there are a number of subtypes, and within the subtypes a number of quasispecies. The frequencies of the genotypes are different in different parts of the world. There are many different genotypes relating to the route of infection, and some genotypes such as 1a, 3a and 4 may be more common in younger persons and type 2a associated with older age. It is still controversial whether genotype is related to severity of the hepatitis, although it has always been found that type 1b is less responsive to treatment than the other types. Each genotype and subtype may be anti-genetically different, another factor making the development of a vaccine very difficult.

The Functions of our Liver

Our liver is reputed to have at least 200 separate functions, some of these functions are;

- To produce quick energy when the body needs it.
- To manufacture new body proteins.
- To prevent shortages in the body fuel by storing vitamins, minerals and sugars.
- To regulate transport of fat storage.
- To regulate blood clotting.
- To aid the digestive process by producing bile.
- To control the production and excretion of cholesterols.
- To neutralise and destroy poisons.
- To metabolise alcohol.



- To monitor and maintain proper level of chemicals and drugs in the blood.
- To cleanse the blood and discharge waste products.
- To maintain our hormone balance
- To help the body resist infection by producing immune factors and by removing bacteria from the blood.
- To regenerate its worn tissues.
- To store iron.

The Striking features of the Hepatitis C Virus.

•The virus circulates in very low concentrations in the blood of most hepatitis c positive people.
•It is also very virulent (very infectious) only tiny amounts of the virus can cause severe illness.
•As it is very infectious, it is easily passed from a carrier via blood to blood contact.
•There can be significant liver damage occurring even though blood tests like ALT are within the normal range.
•It both triggers and mimics autoimmune disease.
•It has a very fast mutation and can evolve into different strains.
•It is very resilient (recovers quickly) and hard to kill on surfaces,- this requires the use of strong bleach.
•The rate at which the virus progresses is seen as highly variable (changeable, unpredictable).

Drugs/Alcohol and our Liver

Everything we ingest into our body, no matter if we are eating, drinking, smoking, inhaling or injecting, it has at some point to be processed by our liver. One important role of the liver is to metabolise alcohol and drugs. All drugs including alcohol, cigarettes and even coffee, are processed by the liver with varying degrees of ease.
Take care to note that some drugs have an adverse effect on the immune system, such as cocaine and crack. This would be likely to produce the conditions in which your viral load could increase.

The effect on the body of dance drugs, such as 'ecstasy' and 'speed' can be exacerbated if we take into account the users behaviour whilst on these drugs, e.g. staying up all night, using lots of energy and not eating or drinking enough will increase the adverse effects of these drugs.

Depression and Hepatitis C

Many emerging illnesses , before gaining acceptance by the medical profession have been discounted as being depression, hysteria etc...Before hepatitis c was identified in 1989, many of it's symptoms were correlated to depression and many un-read doctors today still believe that the Hepatitis C virus is usually asymptomatic. One other issue is that hep c positive patients can get 'secondary depression' if their lives have been disrupted because their illness has interfered with their work or their social or even family life. With this indirect consequence of the illness may be taken by some medical professionals as indicating a cause rather than an affect of the observed symptoms. An article written in 'Hepatology' June 2000 p.1207-1211, vol.31, no 6 "Hepatitis C, Interferon and depression". The writers have noted that two separate lines of evidence support an association between HCV and depression. Firstly patients with psychiatric disorders have a higher level prevalence of HCV infection. Secondly patients with chronic hepatitis c may have a higher prevalence of psychiatric disorders including depression.

Mood Changes

Dealing with a chronic disease: There are many people who never really appreciate their health and fitness until they have to face the fact that they now have an illness that is not going to go away. Dealing with this new problem can make you feel angry and depressed and it is hard to get past the thought of 'why me' Many people normally experience five stages of adjustment as they learn to accept they have a chronic illness. There are feelings of denial, anger, depression, bargaining and acceptance. All of these feelings are natural and there is no set time for your journey through each stage and so often the stages overlap.

Accepting:

Realising that you have to experience the pain in order to be able to get through it. Try not to hide your emotional and physical hurt, just experience the hurt and then let it go, never be afraid to express the hurt you are feeling. Learn how to laugh and bring humour into your situation and try to enjoy the simple little pleasures in life. Do not cut yourself off from friends and family, it's sometimes nice to know someone is listening and understands how you are feeling and can maybe lighten your load. Remember not to neglect yourself, have some quality time just for you, being alone can provide a personal perspective from which you can make calm, sensible judgements and gain personal growth, giving a positive outlook on life once again. Never hesitate if you feel the need to seek counselling as some problems are often too big to work on by yourself. Take control and be responsible for yourself as you **do** play a role in your illness.

Coping with low energy levels: Irritability:

Anger is known as a side effect to liver disease and about feeling sick and tired and aching most of the time does not help. All that helps is to slow down, but most of us find it difficult to do as if we did slow down how would we feed ourselves or pay our rent or bills. People suffering from symptomatic HCV should be on a disability benefit. They should also have home care and day care provided for their children if needed, also help with cleaning their homes, cooking and shopping. When you are feeling tired, sore, sick or dizzy, being caught up in the day to day aspects of life becomes increasingly difficult. Sometimes you may feel so heavy so that when you are overwhelmed by your doctor, social security office or your employer then it is no wonder you might just explode. The best thing to do is have a friend with you who understands and also why not try joining a local support group this can really help. Remember you are not alone.

THE MILLENNIUM COMMISSION
A MILLENNIUM AWARD SCHEME
SUPPORTED BY FUNDS FROM THE NATIONAL LOTTERY

Alternative Therapies

Traditional Chinese Medicine

Today there are various Chinese medicines that may help your liver and also reduce inflammation and also help you to detox from drugs if you have the desire to do so.

A Few Commonly Used Herbs For Hepatitis C

CHAI HU, CAI HU. (Chinese bupleurum)

One of the finest for detoxifying the liver. It reduces feverishness and sweating.

HUANG LIAN. (coptis root)

An anti-viral herb, also has a mild sedative effect.

BAI ZHU, PAI SHU. (rhizoma atartylodis)

Stimulates enzyme production, supports digestion process. Lowers blood sugar level, and promotes the release of excess fluids via urine.

ZHI KE (bitter orange)

Softens hardening in the gastro-intestinal tract. Helps prevent constipation and stomach aches.

FANG FENG (sileris)

Relieves pains in the joints, flu, headaches, chills and rheumatoid numbness. Great tonic for immune system.

PANG GUI, DONG QUAI. (angelica root)

Improves circulation and nourishes the blood.

BAI SHAO YAO (white peony root)

Liver tonic, helps stop night sweats and relieves hypertension.

BAN LAN GEN (isatis root)

An anti inflammatory, eliminates excess heat and toxins from the blood.

Please Visit your local Traditional Chinese Herbalist

for further advice on the above.

Good practice in Pre and post Test Counselling

Pre-Test

- GP has good up to date knowledge of HCV.
- Test should be explained — initially an antibody test.
- Risk behaviour outlined
- The patients risk.
- Implications of a positive test result.
- Implications of a negative test result.
- Window period.
- Does the patient have any further questions.

Post - Test

- Session timed to allow patient to digest the result.
- If negative does window period apply.
- Give prevention advice — how to avoid passing it on.
- Does the patient wish to take it any further.
- Explain what further investigations might be necessary.
- Supply up to date literature available and discuss any issues.
- Discuss what treatment is available.
- Give details of support group and where available

Treatments for HCV

Time seems to crawl when you are waiting for something to happen, like a new treatment for hepatitis C. Sometimes it may seem that nothing is happening. But, be assured it is also of great importance to researchers, who are working to find answers to the viral puzzle called "hepatitis." Did you know that there are a number of new liver disease treatments currently in various stages of clinical trials?

"What are my treatment options?" is probably one of the most frequently asked questions, along with, **"When will there be new treatments available?" C**ombination therapy of pegylated interferon and ribavarin, is now the standard treatment protocol for hepatitis C. Some of the side effects, which include fatigue, muscle aches, headaches, nausea, weight loss, irritability and depression, may be difficult for some patients to cope with, but the percentage of stopping due to this is very low.

So, what are our options?
At this present time patients have few choices. It's the combination treatment; or wait in hope that something new will soon be available. If you are mildly chronic, with no evidence of fibrosis or cirrhosis, then waiting might be the best option, especially if you are genotype 1, which has proven to be the most resistant to current therapy. However, if you have signs of scarring, your Doctor may recommend that you consider treatment now to try to stop or at least slow down the progression of liver damage. And, for the immediate future, interferon-based treatments will continue to be the standard of treatment.

What are Interferons?
Interferons were first discovered in 1957, and are produced naturally by human cells in response to viruses, tumors and foreign substances that can cause the production of antibodies. They "are members of the family of glyco proteins, classified as cytokines, which contribute to the body's natural defences against foreign substances," according to the "Frequently Asked Questions" site found at the Interferon Sciences Inc. Website. Interferons have been found to have an antiviral effect or to interfere with a virus's ability to replicate itself in the body. Researchers have identified four major classes of human interferons: alpha, beta, gamma, and omega, but only alpha and beta have proved the most useful in medical applications. Alpha interferons have become one of the most important classes of therapeutic products in the world.

Cont from overleaf...

Treatment for HCV

Pegylated Alpha Interferon

Pegylated alpha interferons are made by attaching a large water-soluble molecule called polyethylene glycol (abbreviated PEG) to the alpha interferon molecule. Attachment of PEG increases the size of the interferon so it takes longer for the body to get rid of it. It also helps protect the interferon molecule from getting broken down by the body' s enzymes. One advantage to the longer lifetime in the body (referred to as half-life) is that the drug does not have to be taken as often. Regular alpha interferons are usually injected three times per week but pegylated alpha interferons only need to be taken once per week. Also, studies have shown that pegylated alpha interferons are more effective in producing a sustained viral response in patients with chronic hepatitis C than their non-pegylated counterparts.

Currently, there are two types of pegylated alpha interferons available: peginterferon alfa-2a and peginterferon alfa-2b. Although both these agents are effective in the treatment of chronic hepatitis C, there are differences in size, pegylation type, half-life, route of clearance from the body, and dosing between these two pegylated alpha interferons. This is because the method of pegylation and the type of PEG molecule used in the process can affect how the interferon molecule behaves in the body and how it is cleared from the body.

As of Dec 2003 NICE (national institute of clinical excellence, England) guidelines state pegylated interferon dosing is now weight based for patients.
You can read the full report @http://www.hepcscotland.org.uk
Getting all the information you can about your hepatitis C therapy can help you understand how it will work and what to expect in terms of side effects and treatment results.

Alpha interferon-based therapy is not right for all patients with chronic hepatitis C. This treatment is associated with serious side effects including problems with pregnancy, mental health problems and suicide, heart, blood and/or body organ problems. Patients must discuss the possible benefits and side effects of treatment with their physician

Ribavarin

Ribavirin is an antiviral drug that is used with manufactured forms of alpha interferon for the treatment of chronic hepatitis C. Ribavirin belongs to a group of drugs called nucleoside analogs, which are believed to prevent viruses from multiplying. Studies have found that the combination of ribavirin and some forms of alpha interferon help to reduce the amount of virus found in a patient' s blood (called "viral load").
Ribavirin by itself has not been shown to be effective against the hepatitis C virus, but in combination with forms of alpha interferon, it is much more active than alpha interferon alone.
Ribavirin, however, is known to cause severe birth defects, so it cannot be used by pregnant women or by men whose partners are pregnant. Patients cannot begin combination therapy until a negative pregnancy test has been obtained just before the start of therapy. Moreover, male as well as female patients who are being treated with combination therapy must use at least 2 forms of contraception to avoid pregnancy during treatment and for 6 months after treatment stops.
Ribavirin also causes a marked reduction in certain blood cells so patients with a history of heart attacks or significant heart disease should not take ribavirin-based combination therapy.

Treatments Looking Good from Trial Results!

The table below shows sustained virological response(% patients HCV negative)
(Taken from the Lancet Vol. 358 No. 9286)

Treatment Regime	P 1.5/R	P 0 . 5/R	I/R
Number of Patients	511	514	504
Response at end of Treatment	65%	56%	54%
Sustained Responses	54%	47%	47%

Sustained Response Rates with Viraferonpeg and Ribavirin

From the table below you can see that using the combination of Viraferonpeg (1.5micrograms/kg/week) and ribavirin was significantly more effective than the combination of Interferon alpha-2b and Ribavirin, particularly in patients with Genotype 1. Sustained response was assessed by the response rate six months after finishing treatment.

HCV Genotype	Rebetrol Dose (mg/kg)	P 1 . 5/R	P 0 . 5/R	I/R
All Genotypes	All	54%	47%	47%
	<10.6	50%	41%	27%
	>10.6	61%	48%	47%
Genotype 1	All	42%	34%	33%
	<10.6	38%	25%	20%
	>10.6	48%	34%	34%
Genotype 1 <_2 million copies/ml	All	73%	51%	45%
	<10.6	74%	25%	33%
	>10.6	71%	52%	45%
Genotype 1 >2 million copies/ml	All	30%	27%	29%
	<10.6	27%	25%	17%
	>10.6	37%	27%	29%
Genotype 2/3	All	82%	80%	79%
	<10.6	79%	73%	50%
	>10.6	88%	80%	80%

P 1.5/R Viraferonpeg (1.5 micrograms/kg) + Ribavirin (800mg)
P 0.5/R Viraferonpeg (1.5 to 0.5 microgram/kg) + Ribavirin (1000/1200 mg)
I/R Interferon alpha-2b (3MIU) + Ribavirin (1000/1200 mg)