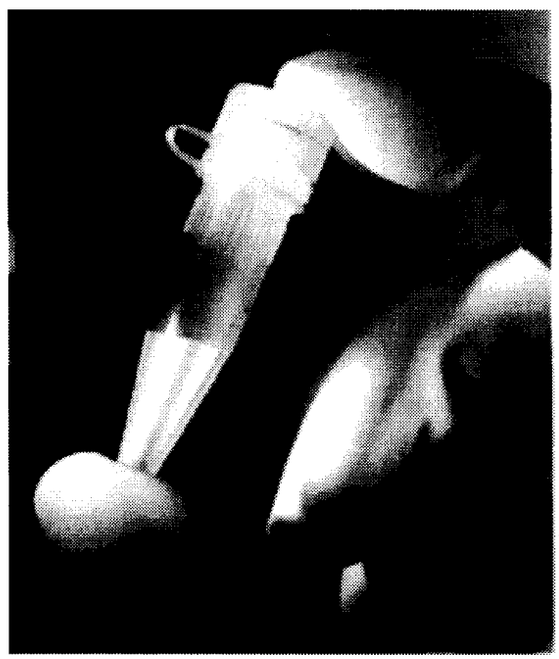
The Hep C Review

Summer Edition February 1998 Issue 20

New awareness of HCV transmission

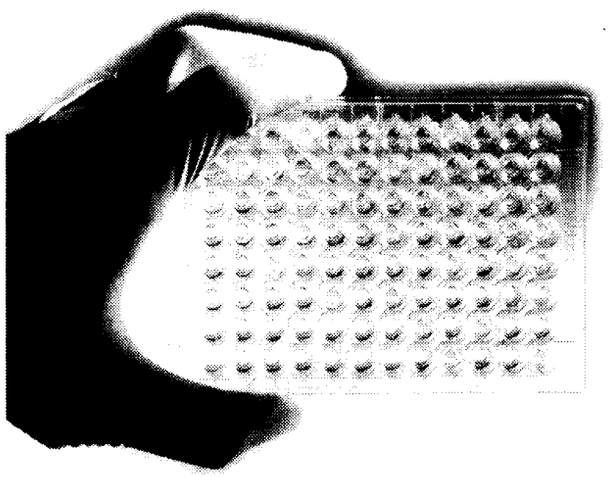
In a research breakthrough regarding transmission of HCV, it has been claimed that PCR testing can, with relative certainty, determine if the blood of a person with HCV is potentially infectious or not.



Researchers at the National Centre in HIV Epidemiological and Clinical Research and the AW Morrow Liver Centre have reviewed the findings of approximately 30 international studies involving over 2,000 cases of hepatitis C.

Among 1,148 instances where people had been exposed to sources known to be PCR positive, there were 148 cases of transmission of the hepatitis C virus. Alternatively, among 874 cases where people had been exposed to sources known to be PCR negative, no definite transmission of HCV occurred.

The review showed that a negative result by polymerase chain reaction (PCR) indicates a person's extremely low probability of transmission of hepatitis C. Until now, it was believed that the blood of all people who returned a positive hepatitis C antibody test result was potentially infectious.



Gregory Dore, one of the principal researchers, said the project was aimed at determining factors relating to transmission of HCV.

"A key issue within management and counselling of people positive for antibody to hepatitis C is their risk of transmitting the virus. For example, counselling of a pregnant woman or a healthcare worker who'd experienced a needlestick injury would be aided greatly by a clearer understanding of the actual risks involved."

This development raises important issues for people affected by HCV and for healthcare workers. To find out more about the implications of PCR testing and its availability, turn to our follow-up article on page 9.

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The Hepatitis C Council is an independent, community-based, non-profit membership organisation. We provide information and support to people affected by hepatitis C and assist in preventing further spread of the hepatitis C virus (HCV). The Hepatitis C Council of NSW is primarily funded by NSW Health.

***MARLTON** comic* (page 5) is by Andrew Marlton, Doggy Times Cartoons: 02 9940 0105

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Who's leading this evolution - nature, nurture or no one?

The emergence of Australia's hepatitis C epidemic has undoubtedly had an impact on our healthcare system here in NSW.

The hepatitis C virus (HCV) has posed challenges for healthcare workers. All have needed general information and updates on HCV, while specific healthcare workers dealing predominantly with HCV have found themselves at the coalface of an evolving field of knowledge that simply did not exist fifteen years ago.

As with other new or evolving serious illnesses, hepatitis C has led to some major initiatives in the delivery of healthcare services.

In the early 1990s, we saw the establishment of national and state HCV taskforces calling for implementation of specific strategies to address the epidemic. It's been no surprise to see HIV/AIDS strategies expanded to try to address the HCV epidemic.

On a national level, we've seen the Australian National Council on AIDS (ANCA) broadened out to become the Australian National Council on AIDS and Related Diseases (ANCARD).

On a state level, we've seen NSW Health's AIDS Bureau expanded to become the AIDS & Infectious Diseases Branch (AIDB).

HCV has led to changed structures within health departments and expert consultative bodies. It has also had a significant impact within the general community far beyond the natural concern over personal safety you'd expect with any newly discovered infectious epidemic.

In the same way that within the general community, HIV/AIDS influenced a reassessment of views on gay and lesbian relationships, HCV has clearly placed the spotlight of public debate on injecting drug use - some would say unfairly so.

In this regard, hepatitis C has become much more than a medical condition to be addressed within the confines of a patient-doctor relationship.

Overall, it has become a major challenge for our community: socially, medically and economically. It is a problem that has developed a complicating cultural and moral reputation through its association with injecting drug use - a worrying problem that is evolving at its own alarming pace.

With HCV approaching its tenth 'birthday' it's time to ask direct questions. People with HCV or those working with it are wondering "who is actually leading the response to HCV?"

Is it some faceless person (or people) in Canberra? Is it Dr Michael Wooldridge, the Federal Health Minister - or is it those people who make up ANCARD?

Here, within NSW, do we look to our Health Minister, Dr Andrew Refshauge, or the Health Department's AIDS & Infectious Diseases Branch?

".. hepatitis C has left us wondering if politicians actually lead the health system, or whether it leads itself and they follow?"

Whoever is responsible for providing leadership on HCV, they must be reminded that the current response is simply not working.

There is an abject failure to stem the incidence of ongoing infections.

Healthcare workers remain under-resourced and effective training programs for workers in the health sector are still yet to be developed.

Meanwhile, people with HCV experience an unacceptable level of HCV-related ignorance, stigmatisation and discrimination.

The main complaint of all workers dealing with HCV is of chronic underfunding. This stems from the short-sighted and tight-fisted approach of Commonwealth and State treasuries.

To prevent the long term needs of an estimated 80,000 NSW people slipping between the gaps, we need to see tenacious, aggressive health ministers prepared to stand up and battle the bean counters.

For many of us who, prior to receiving an HCV diagnosis, had little real interest in NSW's healthcare system, hepatitis C has left us wondering if politicians actually lead the health system, or whether it leads itself and they follow?

Political approaches to address the situation here in NSW have been canvassed, including calls for establishment of a cross-party Parliamentary Taskforce and the upgrading of the current NSW Hepatitis Advisory Committee to that of a direct Ministerial advisory body. But whatever specific approaches are adopted, what we really need is effective, committed leadership.

SOS - 'start our support'

I am sending you a copy of the letter which I have sent to Parliament (see p31). It was your letter to "Dear Friend" which helped me to decide to submit my personal submission.

I am also writing to you for another reason: if you read my submission you will notice that there is no support group in my area. I want to change this as I'm sure that I am not the only person in this district to have hep C.

Can you please tell me how I should or could go about setting up a support group for people with HCV and their friends/family.

A lot of people don't even realise that the Council exists - and they probably feel as alone and isolated as I do. And anyway, what I'd love to see is some sort of local support group.

Also, I want to take an active involvement in enlightening the public about hep C. I would appreciate any guidance you can give me,

Yours sincerely - Lisa

[For information on support groups, see pg. 6]

love me, love my PC

I'd like to draw everyone's attention to an internet hep support group called HEPV-L.

It is a mailing list which is world-wide and provides its members (currently around 1,100) with information, support and communication with people affected by hepatitis. Most on the 'list' have hepatitis C.

Anonymity is up to the individual - you can just use your first name if you like.

While it is not censored, there are rules of etiquette that need to be respected - such as mutual respect, no abusive language, etc.

It is run by a group of very fine list owners - good people who have hep themselves.

To subscribe as a member of the list and start receiving mail, just send an email to:

LISTSERV@MAELSTROM.STJOHNS.EDU

In the body of your email message, you need to type:
SUBSCRIBE HEPV-L (followed by your name)

As an example, Joe Bloggs could write:
SUBSCRIBE HEPV-L JOE or
SUBSCRIBE HEPV-L JOE BLOGGS

I have found this a unique and fantastic source of up-to-date information on current research results world-wide, medication options, all types of relevant info. Also I've struck up some friendships via email with people who are in a similar situation, and have received and offered support to many on the list. It's an opportunity to share personal experience and vent feelings too.

Obviously, this will be of interest to the limited group of people who have internet access. It may encourage people to get that access. Many of us may be able to use computers in our workplaces.

I'm very busy at the moment, but will write more on this whole idea soon.

Love - Donna

treating cholesterol

I'm aged in my late 60s and my doctor recently suggested I start taking a prescription medication called Questran to help with my elevated cholesterol levels.

Although my hepatitis C isn't much of a problem and my ALTs are close to normal, I'm concerned about Questran's effect on my liver. My doctor didn't tell me much about it. Can you tell me more about Questran?

Regards - Bernie

[Questions like Bernie's should really be answered by a healthcare worker. So, if you have similar questions, please

first ask your GP or specialist as we don't have such medical staff here at the Council. Bernies' situation also highlights why it's important to disclose hepatitis status to doctors. Without this knowledge, they may not be able to prescribe the best medication for any ailment you have.

We did speak to a couple of gastroenterologists who said that Questran itself doesn't raise cause for concern as it is a substance that remains in the bowel and doesn't enter our bloodstream. It sits there binding up bile acids and leads to lowering of blood cholesterol and is seen as quite safe for people with hepatitis - Ed.]

just thanks

Hi, I'd just like to thank you for your magazine. I feel like lots of people out there who, like me, find the information and support of great help.

Love from 'K' in Victor Harbour

hi Melinda

I'm Bobby and I'm writing to Melinda whose story in the Review (Ed 19, page 34) I deeply related to.

I was diagnosed 9 months ago but know I've had it several years. I had a history of alcohol and drug abuse and I used those for 18 years. I am 35 years old and have been clean and sober over 2 years, thank God.

I was going to die I was told if I didn't stop. I thought being clean would get my health back but I've been sick with chronic tiredness, liver pain, diarrhoea, constant nausea and dizziness.

For years I've seen dozens of doctors who would not believe I had a physical illness. I was constantly told it was all stress and depression. Then I was told it was all in my head. The only reason I was tested is because I kept demanding a blood test as I had alcoholic hepatitis and also hep A when I was using. Anyway, after shopping for a good doctor, I've found one who treats me as a whole person. I am still unwell but I have hope and I am changing my diet and having one-to-one counselling.

I have a lot of prejudice in my neighbourhood and my mother doesn't want me near her even after I gave her information.

I believe people still think it is AIDS. I wish and hope there will be community awareness in our suburbs and there'll be no more stigma.

Some doctors and friends are prejudiced as well but I've decided to accept that they don't have enough education and it's not their fault they feel this way.

So I am moving on and I'm going to fight this HCV. I went to extraordinary lengths to clean up my act and I'll do the same to beat this disease.

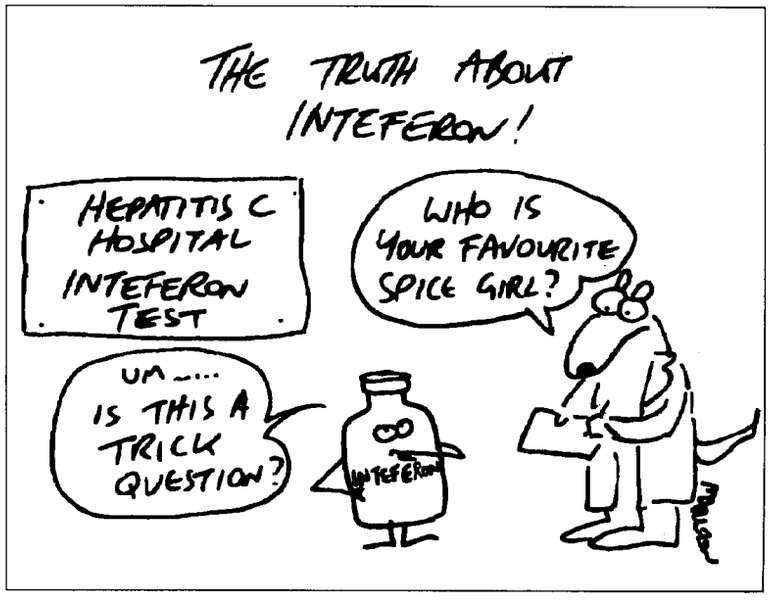
There are no support groups in Blacktown but I'd like to know if there are any close by. Could someone help me? I am asking you all no matter how heart wrenching rejection can be.

I know if I have hope and faith in whatever, I will cope. I'm not religious but I believe in spirituality - a relationship with my Higher Power. I pray there will soon be a cure for HCV and that we will all gain strength.

I always try to remember, no matter what illness we have, we are HUMAN.

God bless, Bobby

[For information on support groups, see pg. 6]



Hepatitis C treatments

This edition of *The Hep C Review* features a general focus on hepatitis C treatments. We hope you find the various articles enjoyable and interesting.

While realising it's impossible to cover all aspects of a topic such as treatments, we've attempted to recruit as wide a range of opinions as possible.

For an overview of the many issues surrounding treatments, you could do no better than read Bob Batey's article on page 15.

One important theme running through several articles and all the personal stories is the reinforcement of the personal nature of this illness called hepatitis C.

The reality of Australia's HCV epidemic is not simply of one illness that far too many Australians have, but also a myriad of 200,000 individual stories about people dealing, or not dealing with their condition.

Support Groups

Recently, a social work student on placement at the Council conducted research into the support needs of people with hepatitis C. She is currently finalising her report and we hope to run an article within Edition 21 - due for distribution in June.

Currently, there are few support groups across NSW. In the meanwhile, if you are interested in finding (or starting) local peer support or therapy groups, we'd recommend you contact your local Infectious Diseases Coordinator. These workers are listed in each edition of The Hep C Review on page 38.

S100 improvements

There is optimism that we'll soon see a relaxation of exclusion criteria for Section 100 interferon (available free through the Pharmaceutical Benefits Scheme).

The Pharmaceutical Benefits Advisory Committee agreed in December '97 that people with hepatitis C who have HIV co-infection or who have recently injected illicit drugs should not be excluded from S100 treatment - as is currently the case.

The development is a result of ongoing consultation between community groups, medical clinicians, federal government health bureaucrats and the National Health & Medical Research Council.

The recommended changes still require Ministerial approval and are expected to be implemented by 1 April 1998.

HCV cloned

In one of the biggest scientific breakthroughs since the 1989 discovery of HCV (hepatitis C virus), two US groups have reported the development of infectious HCV clones.

Scientists from the Washington School of Medicine and the National Institute of Health have demonstrated their ability to transmit hepatitis C to chimpanzees using hepatitis C virus RNA (genetic material) derived from cloned hepatitis C virus DNA (another type of genetic material). Their work has been published in the prestigious journals, 'Science' and 'Proceedings of the National Academy of Science'.

To date, many efforts to study the virus life-cycle have been hampered by the inability to 'grow' the virus in a laboratory setting. Viruses, unlike many other micro-organisms, cannot multiply on their own. They need to invade a host cell and hijack part of the cell's genetic material to make more viruses.

While we can grow many different types of viruses in special cell cultures in a laboratory, this method has proved unsuccessful with HCV. The production of infectious RNA means that it will be possible by molecular means to infect laboratory cells. This will mimic many facets of the way the virus multiplies within human beings. Researchers will then be able to better investigate unique virus targets for drug design, examine questions about virus evolution and what kills it and determine factors relating to viral clearance.

A pleasing development is that although the use of the infectious clones has clear commercial implications, both groups are willing to allow other researchers use of the material for basic research under appropriate legal agreements. It may be some time before the benefits of the research have practical applications but it is certain we will look back on this work as one of the milestones in hepatitis C research.

(Abridged from an article by Scott Bowden, Victorian Infectious Diseases Reference Laboratory, printed in The Good Liver, Nov. 1997)

HCV gets frequent flier points

There is belief within the scientific community that hepatitis C has spread around the world through the development of blood transfusion techniques since the 1920s and, in certain countries, through the practice of mass vaccinations where multiple use of unsterilised needles led to the spread of HCV.

More recently, an explosion in international air travel and the sharing of injecting drug equipment among people who inject drugs have led to further global spread of the virus.

From the estimations of mutation rates (how much and how quickly the virus naturally changes) among the different strains of HCV, it is believed that the main genotypes diverged from an original strain at least several thousand years ago, with the emergence of today's subtypes, 200-400 years ago.

It is ironic that the development of transfusions and vaccinations which has led to the saving of so many lives may also have contributed to the spread of what has become one of the world's largest growing viral epidemics.

(Abridged from a article by Rhonda McCaw, Victorian Infectious Diseases Reference Laboratory, printed in The Good Liver, Sept. 1997)

Role of PCR reviewed

The Australian Health Technology Advisory Committee recently released a report, *Review of nucleic acid amplification technology*. The report outlines recommendations on the appropriate use of HCV tests based on nucleic acid amplification (NAA).

Nucleic acid amplification tests look for actual presence of the hepatitis C virus. The two best known NAA tests are known as 'PCR' and 'branched DNA' testing.

Finding that in some cases, NAA tests for HCV significantly benefit diagnosis, counselling and treatment, but that wide scale use is unlikely to be of further benefit, the AHTAC report recommended that: *NAA be used for the diagnosis of HCV in cases in which information on the level of virus in the blood is required and where it will affect patient management.*

Stating that NAA techniques provide reliable measures of suppression of HCV during interferon therapy, the report highlighted that at present no evidence exists to indicate whether this correlates with long term clinical benefit. Adding that initial and serial HCV testing can measure the response to interferon therapy, AHTAC recommended that: *evidence on the value of NAA methods for monitoring HCV progression is unclear and further evaluation and monitoring are required.*

It's important to note, though, that a considerable body of evidence has been published in the time since the AHTAC report was prepared.

Martyn Goddard of the Australian National Council on AIDS & Related Diseases' Clinical Trials and Treatments Advisory Committee (CTTAC) reports that they are putting a major submission to the Commonwealth Dept of Health detailing this research.

"The evidence supporting the clinical value and cost effectiveness of HCV viral load testing is now overwhelming," he stated.

(For more info, see page 30.)

USA approach to treatment

Dr Jay Hoofnagle, Bethseda, Maryland, USA, recently presented a review of the recommendations of the Consensus Development Conference on Treatment of Hepatitis C, at the United States National Institutes of Health (NIH).

Therapy recommendations

Interferon, at 3 million units, 3 x weekly, for 12 months is now recommended for people with HCV at risk of developing cirrhosis. A positive PCR viral detection test, raised ALT levels, and a biopsy result showing septal fibrosis or inflammatory changes all being indicative of risk of cirrhosis.

Genotyping

The Committee referred to the importance of genotyping, which is recognised as a possible predictor of response to interferon treatment. Studies have suggested that HCV genotypes other than 1b are more likely to be associated with sustained response to treatment.

Monitoring of disease progression

The committee recognised that PCR viral load testing can detect very low levels of virus during interferon treatment. Resolution of elevated ALT levels during interferon treatment was still considered an important indicator of disease response, although there is only a weak correlation between ALT levels and liver damage - indeed, substantial liver damage can occur at normal ALT concentrations.

Measuring therapy efficacy

Effectiveness of interferon treatment is defined 'virologically' as loss of HCV in the blood - ie. an undetectable viral load - and 'biologically' as normalisation of ALT levels, with both tests being measured at end of treatment and 6 months later.

Factors indicating a good therapeutic response

Most importantly, a low blood level of HCV (defined as a viral load of less than 1,000,000 'copies' per ml of blood - copies are like pieces of HCV) and having HCV genotypes 2 & 3, indicate a good therapeutic response to interferon. Absence of cirrhosis is also considered a good indicator. It is noted that having high HCV viral load and/or genotype 1b were not adequate reasons for withholding therapy, despite their being predictive of a less favourable response.

Relapsers

PCR negative relapsers are eligible for additional interferon using the same regime, while PCR positive relapsers are not recommended to receive more interferon monotherapy treatment.

The future

The NIH committee felt that the future of HCV treatment lies in the development of more effective therapies and a vaccine.

(Above information relates to the USA and is provided as a guide of what's happening overseas. It is abridged from Congress Reporter, May 1997, European Association for the Study of the Liver)

DSP study project

Although many people with HCV will not need to access the Disability Support Pension, for those people who do, it can be a difficult situation.

We've realised that many people have a wide range of personal experiences with the Department of Social Security. If you access a Social Security benefit or pension because you have hepatitis C, we'd like to hear about your good or bad experiences. Through this project we may learn of other aspects of Social Security that need review and change - and those that need to be retained.

If you provide personal contact details within your story, these will be kept strictly confidential. Please send your story to:

DSS Project
Hepatitis C Council of NSW
PO Box 432
DARLINGHURST NSW 2010

Disability Support Pension update

Following extensive lobbying by community groups and others, the Federal Government has favourably amended Social Security legislation that could have adversely affected people with fatigue related conditions.

The government's original proposed changes - as reported in our Editions 16 & 17 - could have made it more difficult for people with conditions like hepatitis C to access DSP. Their changes related mainly to the impairment 'tables' that are used by departmental officers in determining the level of disability a person experiences.

The government's changes were part of a Social Security Bill tabled in Parliament last year. Due to Senate resistance by Opposition and Independent senators, the government initiated a last minute round of consultation providing an opportunity for us to make a detailed constructive submission. Many of our recommendations were adopted by the Government in their final changes to the impairment tables.

We'd like to thank the many people involved in this successful campaign - John Mackenzie, who was a driving force behind the campaign, all our members who wrote to politicians, those members who volunteered as case studies within our parliamentary submissions, Welfare Rights Centre, and all others involved.

New interferon trial gets the go ahead

Reflecting a determination to further optimise response rates to interferon treatment, researchers are about to begin a nation-wide trial involving 'loading dose' therapy.

Targeting people who've not previously had interferon treatment, the trial involves 48 weeks of treatment. The first 4 weeks will involve 6 million or 9 million units, daily (interferon is normally given at 3 million units, 3 times a week).

The trial is open to people regardless of whether they have cirrhosis or not. All will be monitored through several PCR viral load tests - and will also have their PCR genotype determined.

One of the largest trials world-wide, the project will involve over 1,000 Australians and 25 treatment centres.

Anyone in NSW wanting to find out more about the trial should phone the NSW Hepatitis C Telephone Info & Support Service:

9332 1599 (Sydney callers) or
1800 803 990 (NSW callers).

Herbal trial mooted

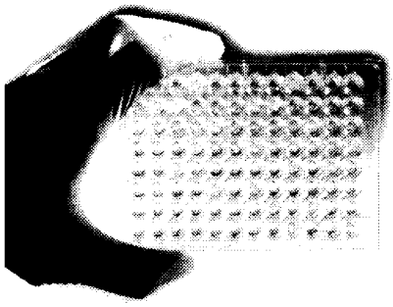
Researchers have confirmed that a second phase of the 1997 Chinese Herbal trial at John Hunter Hospital, Newcastle will go ahead subject to final approval.

To be located in the Northern Rivers area of NSW, the 6 month trial will include around 200 people randomly allocated to either taking the actual herbal formulae or taking harmless, identical looking pills (placebo).

By comparing results from both groups, researchers hope to further examine usefulness of the CH100 Chinese Herbal formulae and its role in dealing with hep C symptoms, and improving people's liver function and quality of life.

People in the trial will be residents of the Northern Rivers region. Researchers hope to begin enrolling people in March, 1998.

PCR & HCV transmission?



For individual people affected by HCV, what are the implications posed by our emerging awareness of PCR technology? (see cover story)

What is PCR?

Unlike hepatitis C antibody tests that look for signs that HCV has entered our body, a PCR (polymerase chain reaction) test looks for actual presence of the virus. There are three types of PCR tests:

- *HCV PCR viral detection test* (looks for the virus, sometimes called *'qualitative test'*)
- *HCV PCR viral load test* (looks for the virus and estimates how many HCV viruses per ml of blood, sometimes called *'quantitative test'*)
- *HCV PCR genotype test* (looks for the virus, and determines the particular type/s of HCV)

Determining potential risk

Although PCR tests have limitations (see below) they do provide benefit for some people with HCV. A primary benefit is in their ability to determine the level of potential risk people with HCV pose to others.

Such awareness will be of great benefit for people concerned about transmission risk associated with pregnancy and childbirth. Of all HCV+ women who fall pregnant, it's believed that their risk of passing on the virus to their baby is about 6%. PCR testing may show that some individual mothers have a next to zero risk of passing on the virus.

This knowledge will also be of help to people who are very concerned about the risk of transmitting HCV through sexual and household (casual) contact.

People who are HCV antibody positive and have fluctuating or persistently elevated liver function test results over the preceding 6-12 months (and not elevated due to some other possible medical condition) are extremely likely to be PCR positive. For these people, PCR viral detection tests would be unnecessary.

Healthcare settings

The technology is also of benefit in cases of needle-stick and other sharps injury in healthcare settings. Healthcare facilities are now beginning to use PCR to determine whether HCV antibody positive healthcare workers carrying out 'exposure prone procedures' pose an unacceptable risk to patients.

Exposure-prone procedures are those with potential for a healthcare worker to bleed into a patient as the result of a sharps injury, eg. surgical procedures in body cavities. The NSW Dept of Health has a longer and more precise definition to guide healthcare workers.

HCV transmission

Even if people with HCV know their PCR status they should still avoid all blood-to-blood contact. In any situation involving potential blood-to-blood contact, it's important for everyone to assume that they, and all others, are potentially infectious. If an HCV antibody positive person finds out they are PCR negative, they'd be making a big mistake in sharing any drug injecting equipment, snorting straws, razor blades or razors, tattooing equipment, toothbrushes or other equipment that could transfer blood.

The key transmission prevention message will always remain to "be blood aware and avoid blood to blood contact". To adopt any other behaviour would place people at risk of transmitting HCV to others, or acquiring an HCV re-infection (ie. infection with a different type of HCV genotype). There is the additional risk of transmitting other possible bloodborne infections, eg. HIV, hep B, fungi, bacteria.

Limitations

Despite improvements in the sensitivity of PCR technology, it's important to assess HCV viral status on the basis of a minimum of 2 PCR tests - over a three month period - rather than on the basis of a single PCR test result.

This is because it is possible for levels of hepatitis C virus in the blood stream to fluctuate. It is possible for the level of virus to fall so low that the PCR test won't pick it up. Thus, someone who tests PCR negative may still be infectious.

People who are currently on, or have recently undergone, interferon treatment need to be especially cautious because of the greater fluctuations in viral levels due to treatment.

PCR technology is more complex than HCV antibody tests. Only specific laboratories are approved to carry out PCR testing.

It is hoped that further research and development of PCR technology will address the above limitations.

Availability

PCR tests are not currently funded by the government and most people have to pay for the tests. Some hospitals provide the tests free to their patients, but this depends on the particular hospital and their availability of funds.

Research has shown how useful PCR technology can be, and adds weight to the argument for appropriate, free access to it.

←

1997's CHICAGO CONFERENCE

by Geoff Farrell

The *American Association for Study of Liver Disease* meeting is the premier international liver meeting. Of 1,400 abstracts presented in December, last year, more than 400 were on the subject of hepatitis C. The greatest interest has been on advances in treatment, on understanding the natural history and clinical outcomes, and unravelling the mechanisms whereby the immune and inflammatory response to the virus infection cause damage to the liver.

Vaccines

There seemed few advances on vaccine development - the single greatest need to halt this epidemic - but two abstracts caught my eye. One study of 40 patients clearly delineated the type of immune response required to clear the virus - mainly participation of CD4+ cells (those that are destroyed by HIV virus). Stimulating this type of lymphocyte would be a novel approach to therapy and could be the key to vaccine development.

In another study, workers from Ann Arbor, Michigan, used DNA technology to see if they could modify the HCV core protein to create a vaccine. Mice were used as an experimental model. A certain type of modification of the protein (insertion of so-called immuno-stimulatory elements - ISS) greatly enhanced the mice immune response, particularly when five individual ISS 'motifs' were designed into the experimental vaccine. This seems to be a novel and exciting step towards developing a vaccine for HCV.

Natural history

Understanding the natural history of hepatitis C - that is, how the disease evolves in individual persons and therefore affects their lives - is of considerable importance. A study of 160 Spanish patients who had been followed for 18 years gave further insights. The only factor that predicted which patients would develop cirrhosis and severe liver disease was the severity of the disease on the initial biopsy. This further emphasises the importance of having an initial liver biopsy done to assess the severity of disease and to allow predictions about the course of the disease; the latter, I feel, is essential to guide decisions about treatment.

While the actual mortality from hepatitis C is relatively low, even over a life-time (perhaps 10%), we know that many people have reduced quality of life. This was recently assessed in 609 hepatitis C cases from Worcester, Massachusetts. Even those people without cirrhosis experienced a markedly reduced health-related quality of life and limitation of social role (ie. breadwinner, parent, etc.) due to physical problems, body pain, and general health perceptions. They also experienced reduced vitality, social functioning, mental health and social role limitations due to emotional problems. Such studies are very important in examining the full impact of HCV on people and populations.

Liver damage

It is now thought that liver damage in hepatitis C is caused by the immune response and inflammation in the liver - particularly with release of host proteins called cytokines. Several abstracts at this meeting provided further evidence that oxidative processes operate in the liver of people with hepatitis C. There is now some early evidence from San Diego workers that oxidative processes can also contribute to scar tissue (collagen) in the liver.

Does this mean that people with hepatitis C should be taking antioxidants? Well, this may be the case, but proper studies are required to see whether taking antioxidants over the long-term will reduce damage to the liver. At least 'pure' antioxidants such as vitamin E do not seem to carry a risk of toxicity which comes with some herbal remedies such as some Chinese herbal medicines. On the other hand, another abstract showed that treatment with Nacetylcysteine (Parvolex) was of no value in patients who had failed to respond to interferon.

47% of patients studied (who had previously relapsed on interferon treatment alone) when treated with interferon/ Ribavirin had a sustained response compared with only 4.7% of those who received interferon plus placebo"

Epidemiology

Even though we have been looking at hepatitis C around the world for seven years or so now, I am still staggered by the epidemiology. In a northern Italian town, more than 10% of the population aged more than 50 years has hepatitis C, whereas those aged less than 40 have a risk between 1 and 1.4% (ie. similar to Australia). The risks for hepatitis C were blood transfusion or surgery in the past, but particularly medical use of glass syringes. These kind of figures are emerging from many parts of the world: Italy, Greece, Spain, the Middle East and Japan. Patients from these ethnic groups have had hepatitis C for 40 or 50 years and they are now comprising those at greatest risk of liver cancer or developing liver failure. More attention should be given to these ethnic groups in Australia. Another study from Los Angeles has emphasised the importance of cocaine snorting as a risk factor for hepatitis C.

Symptoms

There is surprisingly little published on symptoms of hepatitis C, and an abstract from Ireland caught my eye. This addressed the issue of fatigue, the most common symptom of chronic hepatitis C, and whether it is related to the severity of liver disease or to autoimmune disorders often associated with chronic hepatitis C. Not surprisingly, people with hepatitis C did have significantly more fatigue compared with healthy controls - but what was interesting was that the perceived functional impact on quality of life was particularly high in patients with genotype 1B infection. However, fatigue was unrelated to the degree (severity) of hepatitis and could not be accounted for by the coexistence of autoimmune disease. We need to find out more about the cause of this common symptom in order to be able to ameliorate it.

Interferon treatment

The high spot of the meeting was undoubtedly the presentation of the interferon/ribavirin re-treatment study that has been conducted internationally - including three Australian centres. The three primary types of response to interferon are *non-response, response/relapse* (response while on treatment followed by relapse) and *sustained response* (essentially a cure with permanent elimination of the virus).

The study involved 349 patients who'd already had *response/relapse* on interferon. Half of them were retreated with interferon plus ribavirin for six months, the other half had interferon and a ribavirin-matched placebo. The results are still preliminary but 47% of those treated with interferon/ribavirin had a *sustained response* compared with only 4.7% of those who received interferon plus placebo.

In patients with HCV genotype 1, the respective *sustained response* rates were 29% for interferon/ribavirin and 3% for interferon alone, whereas among those with other genotypes (usually type 2 or type 3), 74% had a *sustained response* with interferon/ribavirin versus 7% with interferon/placebo.

These are very good results for interferon/ribavirin. Readers should appreciate that there are now several studies, including two new ones presented at this meeting, which show that patients who had six months interferon and experienced *response/relapse* can be treated for 12 or 24 months with interferon and have at least a 40% chance of a *sustained response*. Further studies are certainly required to see if six months interferon/ribavirin is better than 12 months (or longer) interferon for those who have had a *response/relapse*.

The down side of interferon/ribavirin is that side effects are more severe than with interferon alone - and because the treatment will be at least five times more expensive than interferon, it will not be appealing for governments to adopt it on the free list. Also, the distribution of hepatitis genotypes vary between countries. With type 3 being common in Australia, it is especially important to do interferon/ribavirin studies in our own country.

Other approaches to treatment

To date, no new HCV antivirals have come into testing but we would all hope that they may appear next year, now that so much is known about the virus enzymes.

Attempts to treat patients by other means than interferon have been disappointing. One tack has been to reduce iron levels in the liver, because a build up of iron seems to decrease the response to interferon. Three separate studies showed that this was ultimately ineffective in improving the response to interferon. Another approach is to add drugs of the arthritis group (NSAIDS) to interferon, but again this didn't help. A lot of people with hepatitis C have heard about amantadine from the Internet. The four or five abstracts on amantadine and its first cousin, rimantidine, found minimal or no response of liver enzymes, and very little effect on the virus itself (there was one abstract which did find some effect on HCV, but this was in the minority). One small study from Italy used triple therapy (interferon plus ribavirin plus amantadine) and obtained some responses, but I have an 'open' view on this approach. In the reported study there were only 10 patients in each group, so don't rush away trying to get your amantadine until we get much better information.

Finally, many workers have tried to increase the initial dose of interferon, and have often added ribavirin in complex combination programs to induce a treatment response in patients who have previously failed interferon. At least two studies showed convincingly that combination high dose interferon and ribavirin substantially and rapidly reduce the level of hepatitis C virus in blood, but to date the sustained response rates have remained disappointing. Further studies are justified for this approach to a group of patients who quite often have significant liver disease.

A cure for hepatitis C?

Can hepatitis C be cured? Some of my patients still seem surprised when I tell them that in fact this is the case, albeit only in a minority of cases. Six or more abstracts at this meeting testified to the value of a sustained response to interferon, particularly when the virus has been shown to be eliminated by PCR testing of blood taken 6 & 12 months after treatment.

In these patients, scarring of the liver diminishes with time and the risk of liver cancer appears to be either completely abolished or extraordinarily low compared with patients who have not had a sustained response to interferon. The issue as to whether a partial response to interferon (response/relapse) diminishes the risk of liver cancer remains somewhat contentious. I think the mounting data is that it tends to delay the onset of cancer without removing the risk.

Reducing cancer risks

The final issue as to whether treatment with interferon, without a response being evident on liver enzymes or virus levels, diminishes the risk of liver cancer is still hard to interpret, although I think the weight of evidence is stacking up against that theory. It is very difficult in the types of studies presented to look at truly controlled data because the patients who tend to have better responses to interferon are those at much lower risk of developing liver cancer anyway - their liver disease is not as bad yet as those who don't respond to interferon.

Growing HCV

An encouraging advance during the last six months is the development of several culture systems employing modified human liver cells in which the hepatitis C virus can be grown. This will allow drugs to be tested as well as the life cycle of the virus to be understood in more detail. I'm sure that we will hear a lot more about this in the next 12-24 months.

In summary, this was a very stimulating and exciting meeting, reflecting the vast amount of international research into hepatitis C.

- Geoff Farrell is Robert W Storr Professor of Hepatic Medicine at the Storr Liver Clinic, University of Sydney at Westmead Hospital.

←

Interferon - side effects & you

Interferon treatment is currently successful in up to one in three cases, but a decision to take up the treatment is not necessarily an easy one.

Perhaps one of the most important initial questions for many people is "am I eligible for free treatment?"

Listed on page 36 are the Section 100 interferon eligibility criteria. Those people not eligible for free treatment would have to pay several thousand dollars for treatment (also see news article, p6).

In a decision to try interferon treatment, along with the above key factor, there's the issue of possible side effects.

During the first month, people have a 90% chance of feeling as though they have the flu - ie. fever, shivering, headache and body pain - but in most cases the body becomes desensitised to treatment and these side effects lessen.

The most common long-term side effects are mild hair loss, lethargy, apathy, mild depression and irritability. People have a 33% chance of experiencing these.

Less common side effects include rashes, headaches, mouth ulcers, bad taste in the mouth, low leukocyte blood count, low platelet blood count, exacerbation of psoriasis and autoimmune conditions such as hyperthyroidism.

Given that side effects make people feel tired and irritable, it's useful to consider the possible impact of treatment on family and work responsibilities.

Many would agree that a decision to take up interferon treatment requires input, advice and support from GP, specialist, family and friends - and employers if people are in a position to discuss their hepatitis C (unfortunately, not always the case).

Ending on a positive note; in cases where interferon is successful, the treatment is obviously a very welcome option. Other articles in this edition outline initiatives that will further maximise interferon benefits.

For more information about interferon treatment and up to date developments, contact the NSW Hepatitis C Telephone Information & Support Service:

phone 9332 1599 (Sydney callers)

1800 803 990 (NSW callers)

PCR & interferon

Although PCR tests have been shown to help predict those people who might respond well to interferon, and who respond well during treatment, these tests aren't yet funded by the government. Consequently, doctors are still generally unable to best predict a person's individual chances for success (see news story, pg. 30).

Current decision-making around interferon treatment is not a high-tech process. If people escape the *exclusion criteria* (see news story, pg. 6 & interferon update, pg. 36), they are given the treatment free - under the Pharmaceutical Benefits Scheme, Section 100.

Current monitoring of treatment involves a series of liver function tests and as long as ALT levels decrease during the first 3 months, people are able to continue with free treatment. This is pretty low-tech stuff as it's recognised that liver function tests are not always reliable.

The development of PCR testing over the last couple of years is now being seen as a major advance in regard to current and future hepatitis C treatments.

PCR genotype testing

PCR genotype testing can determine what subtype of hepatitis C virus a person has. This is useful information, as it's been shown that of the six known major sub-types, interferon works better on people with genotype subtypes 2 or 3.

People who are really keen for interferon may not worry too much about PCR genotyping, but for those on the borderline who aren't really sure whether to try the treatment or not, such a test result could really help guide their decision.

PCR viral load testing

PCR viral load testing estimates the amount of hepatitis C virus circulating in someone's blood. The use of these tests during treatment can help monitor whether interferon therapy is working well or not.

Instead of relying on measuring ALT - a potentially unreliable sign of liver function - people can now use a test that will measure the amount of virus in their blood. With interferon being designed to kill the virus, it certainly makes more sense to measure death rate of the actual virus as opposed to simply measuring liver function.

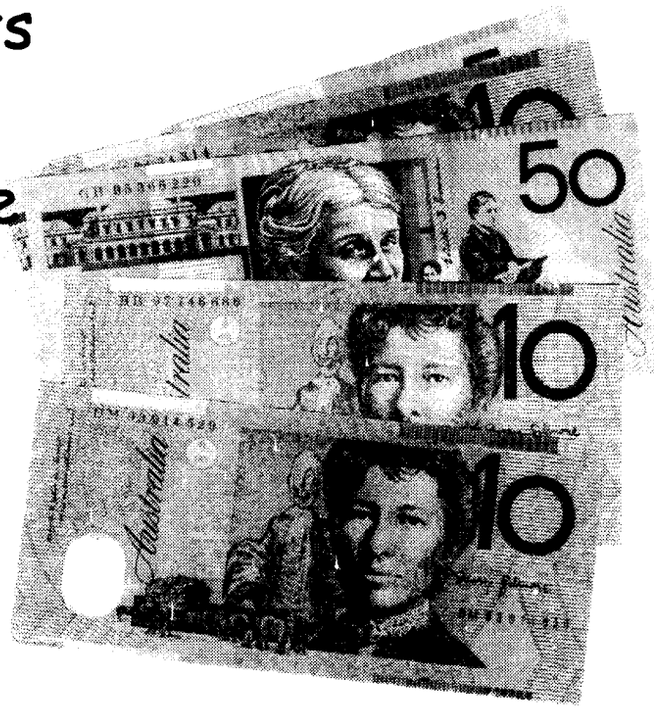
It's also believed that initial PCR viral load testing as early as 2-4 weeks into treatment will identify people who wouldn't respond over the full 12 months.

Availability

With the genotype test costing around $75 and the viral load test costing $100, a course of four PCR treatment-related tests could cost people around $375.

As PCR testing is not covered under Medicare, GPs won't be able to cover the test costs. Some hospitals have limited funding available that enables them to provide the tests free to their patients (see *The Hep C Review*, Edition 19, page 32).

Governments reap drug dollars while services suffer



The Alcohol and other Drugs Council of Australia (ADCA) has released a report from a national survey of over 220 drug experts who rated each government in ten key areas of drug policy and programmes.

The report titled *Drugs Money and Governments 1995-96* is the third national review of government responses to drug problems.

Speaking at the release of the findings, David Crosbie, ADCA Chief Executive Officer, reported that while the Northern Territory government continues to lead Australia, particularly in response to alcohol related problems, most other governments in Australia have failed to actively respond to drug problems."

The report also detailed government income derived from alcohol and tobacco taxes and excise fees, and government expenditure on drug programmes and services.

Findings indicate that while tobacco and alcohol revenue has increased by almost $1 billion in the last 12 months to a total of over $7.3 billion, expenditure on alcohol and other drug programmes has actually fallen in comparison with last year, down to $161.5 million.

The report points out that drug problems cost the community more than $18 billion dollars each year, and calls on governments to spend more to address drug problems through treatment, prevention and research.

On average, each and every Australian is contributing over $400 in drug taxes to governments, while governments are spending less than $9 per head through their respective drug strategies to reduce drug-related problems.

Crosbie suggested the report confirms that our governments are now dependent on drugs. "Perhaps we could live with that, if governments were also committed to reducing drug problems," he said.

The reality is that most governments in Australia are turning their backs on drug problems, and keeping their hands firmly in their pockets.

"When will governments learn that investments in the treatment and prevention of drug problems actually save the community money and lives?" Crosbie said.

The ADCA report also recommends governments involve more experts and community groups in decision-making, and provide more education and professional training on drug issues.

Government	per capita spending	comments
NT	$67.73	Continues its commitment to reducing alcohol problems, but there is room for improvement in other oreas.
ACT	$11.85	Has shown improvement in some areas but has not realised potential of working with drug agencies.
Tasmania	$8.32	Although spending is up, Tasmania's commitment to drug & alcohol problems is poorest, overall.
WA	$7.48	Commitment to responding to the Taskforce Report on Drug Abuse has not improved.
SA	$7.24	Reluctance to include NGOs in decision-making processes continues to cause significant problems.
NSW	$7.06	Has a clear lack of commitment. Continues to perform poorly in areas of planning and treatment. Provision of information to community has emerged as a key weakness.
Queensland	$5.07	Continues its poor performance in identifying problems and developing treatment and prevention programmes.
Victoria	$4.59	Continues to perform poorly. Hopes for changes in response to Pennington Report have not been realised.
Commonwealth	$2.05	It's feared that Departmental restructuring will see D&A programs further lost in broader public health issues.

• *This article is abridged from a recent media release from the Alcohol & Other Drugs Council of Australia.*

The Call

Our real life transplant story continues from editions 17 & 18. After months of waiting, following a late night phone call, Sharon has been rushed to her San Francisco hospital. She now awakes following 12 hours of surgery ...

I knew I was on a ventilator, something I'd worried about before surgery as I'd read you feel like you're not getting enough air. But it felt OK. Finally, I could open my eyes and try to motion to my family. They looked so tired. I wanted them to get some rest. They had now been up over 24 hours and I'd had a 12 hour 'nap'.

Shifts changed in ICU and I became more and more thirsty. They took the ventilator off but I couldn't have more than a piece of wet foam to suck on. I kept thinking about a huge Pepsi with tons of ice. I asked every doctor who came in if I could have something to drink. They all explained it would make me sick until I had some bowel sounds!

My surgeons Dr So and Dr Concepcion came in. They were ecstatic over my bile bag. "Great bile, you're making great bile." I had a bag attached to my right side collecting bile. I had three other tubes collecting drainage. I looked like I had hand grenades attached all over (we won't go into details about the Foley catheter.)

The nurses were very insistent on deep breathing and coughing. Ouch! The anaesthesia had worn off, and there was pain. Pain like I had never experienced before. The doctors seemed to think I was experiencing more pain than most. Some transplant patients have no pain at all. They gave me morphine in the IV. I had a great deal of concern over this as I didn't want to do anything to damage my new liver. The doctors assured me they would monitor this closely.

The second day in intensive care a priest came in and asked me if I wanted communion. They had just made me get up and move to a chair. Being in a great deal of pain and trying to manoeuvre with hand grenades hanging all over you is not an easy feat. Needless to say, I was not in a good mood. "Get out," I said. "God and I are getting along just fine." Later, when I was on the sixth floor, I apologised to the good priest... he smiled and said he understood.

The second night was my worst night. I started shaking uncontrollably; I was having trouble breathing. I knew I was going to die. My daughter summoned a doctor. He stood at the end of the bed as I shook until I levitated. (Well, that's how it felt to me!) He stroked his chin and watched me. "Don't tell me I am just having a panic attack," I yelled. They gave me an injection of Ativan - a sedative.

One thing my doctors got very upset with was the amount of company I had. The first two days, lots of people came to see me. Not a good idea! But at the time, I was extremely grateful for it. One of the side effects of the drugs is insomnia. I hadn't been able to sleep since I came out of surgery. Actually, it would be eight days until I slept two hours straight. The doctors felt I needed rest. They told my family and friends to cool it.

The third day, I was moved to the sixth floor and I had bowel sounds. Passing gas became the ultimate accomplishment. I got to have sips of water. Yippee! By day four, I was exercising going up and down the stairs (slowly).

Then day five arrived. The pain was unbearable. The lack of sleep was getting to me. My numbers were going up. The Rejection word was voiced. Dr Bedford did a biopsy and the results were - I was in rejection. That day my husband brought me some mail from home. A manuscript I had submitted to Silhouette books was rejected. My friends who had been told I needed rest not only didn't visit - they hadn't called for two days. The word Rejection loomed everywhere.

I was given the BLAST, massive steroids to stop the rejection; I didn't come off the ceiling for days. I was spun and speeding faster than a bullet. I walked the halls at night hoping to find someone awake. I couldn't sleep. My eyes wouldn't focus long enough to read. They wanted me to eat and I had no desire for food.

The BLAST did the trick. My numbers started coming down. By day seven, they said I could leave the hospital for the apartment across the street. Then my temperature went up. I couldn't leave until it was normal. If I had left on day seven, I would have broken the record for the shortest stay after transplant. I wasn't into breaking records; I was into keeping this liver.

Soon they were talking about my leaving. Before you can leave the hospital, you have to know your medications. By this time, I had only one tube left, the bile tube. This would be capped off but stay in for three months.

We stayed in the apartment for thirty days. With my Mom's great cooking, I started to eat. Each day I felt better. Twice a week I had post-operative clinic, blood work and transplant support group, so I had to get dressed and get out.

Filmore Street is one block from the hospital and has plenty of shops. We walked the hills of San Francisco every day and made our way to the grocery store, shops and restaurants. Day by day, I got stronger. I had a horrible bout with headaches: the Program (anti-rejection drug) is the culprit for that. Once the dose was lowered the headaches were less frequent.

My daughter, Debbie stayed for three weeks, what a joy. My daughter, Samantha, who's in college in Maine, wrote a paper on Liver Transplantation for her English class. It was her way of being part of the process.

I got a pass for Thanksgiving. It was truly a time for thanks. A week later, I got to come home. It was hard leaving California Pacific. I had become friends with several other transplant families. It was also a huge safety net to be so close to the hospital.

It's been four months since my transplant. Tony and I are getting along just fine. I went back to work three days a week last month. I feel wonderful. I'm walking daily with a walking partner. We're up to three miles.

Each morning I wake up and thank God. Life is good today. I am very grateful for my donor and his family and the transplant team at California Pacific.

I'm also extremely thankful for the bulletin boards on the internet. The hep C and transplant boards were my life line when I was too ill to connect with the main stream of life. The knowledge and concern I received was invaluable. I also truly believe that God has stage hands and we never know what is going on behind the scenes. He has a plan and it is perfect. So don't quit before the miracle.

Regards, Sharon McGow

As we've mentioned after each of our previous instalments of 'The Call', less than one in ten people with HCV will ever experience what Sharon went through. Also as promised, we've approached the Australian National Liver Transplant Unit who've provided the information update, on page 16.

Hepatitis C treatment - where are we now?

by Robert Batey

Treatment of hepatitis C has become a major issue for thousands of people in this country over the past nine years. What can be said about it that is not repetitious, esoteric, boring or unhelpful? While I have not treated as many patients as some of my colleagues, I have overseen the management data on all the patients on the S100 scheme. My ongoing contact with patients prompts the following thoughts about treatment:

High expectations .. fear .. frustrations .. difficult communication .. unhearing doctors .. unlistening relatives. Is there a cure? What is a cure? I don't believe there is a cure! Does the virus come back? Should I have treatment? What is treatment? Do I have to have the drug interferon? What is interferon? How is it given? By injection? Who gives it? ME???

Can't I use herbal medicine .. St Mary's Thistle or anything else? Do I need interferon? Is there anything else? I've read about ribavirin - something on the Internet! Can I get the new drug? What about your trial of herbal tablets?

Resignation .. acceptance .. liver biopsies .. pain .. good biopsy reports .. bad biopsy reports .. counselling .. fear again .. decisions .. needles .. needle disposal .. refrigerators .. restricted travel .. got to keep the drug cold! Defrosted fridges .. rellies seeing the drug in the fridge .. loss of privacy .. side effects .. you mean there are side effects?

More fear .. hope .. statistics on outcome .. more side effects .. hair loss .. what is a thyroid? Headache .. depression .. suicide .. what's going on? Am I doing all right? What do you mean RELAPSE? Is there anything else I can try? I'll try anything else! I have tried everything else - what now! What really are the risks if I don't respond? Herbal decoctions really stink. How could you drink that stuff?

What is the liver cleansing diet? I shouldn't drink coffee should I? Frustration .. anger .. disappointment. You said I was doing well, why have I failed?

Treatment centres overcrowded .. long waiting lists .. advice on counselling .. lack of resources .. competing practitioners .. endless committee meetings .. bureaucracy .. government policies .. drug companies .. drug trials. Hope for the future BUT through all this I see people, in need, in despair at times, seeking help and praying for some relief from their personal struggle with this draining, unremitting disease.

Progress is occurring but it is slow and erratic. We do need to pull together better as our one aim is the better treatment of our patients. I too pray that the coming year will see us better placed to offer optimal therapy to all our patients with hepatitis C.

- Robert Batey is Director, Dept of Gastroenterology, John Hunter Hospital, Newcastle.

Oz transplants

Introduction:

It should be remembered that few people with hepatitis C will ever require liver transplant - less than 1 in 10. The following information is provided for general interest only. If you feel you want more information about liver transplant, please speak to your specialist or GP.

Assessment:

Prior to liver transplant a person will be monitored by their doctor or specialist. This is important as the operation is best undertaken when a person first experiences chronic liver failure - as opposed to the later stage of terminal liver failure.

When the effects of chronic liver failure begin to develop, a person is admitted to Royal Prince Alfred Hospital (RPAH) for a five day "assessment for transplant".

Assessment generally involves the following: blood tests including haematology, cross-matching, tissue typing, hormone levels, hepatitis, CMV and HIV; X-rays including chest, bones and liver blood supply; CT scans of the bones and liver; and an ECG.

As a general rule, there are four basic requirements which indicate someone is suitable for transplant:

- irreversible, progressive liver damage,
- a non-response to all other forms of medical and surgical treatment,
- absence of other major diseases, and
- ability to understand the nature and risks of liver transplantation.

People being assessed are visited by eleven different healthcare workers and are offered the opportunity to meet with someone who has already had the operation.

Final assessments fall into three categories with people being reminded of their right to choose NOT to undergo the operation:

- suitable for immediate transplant,
- suitable for future transplant (this may be months or years away), and
- not suitable for transplant (usually because of a high chance the person would not survive the operation).

Waiting:

Once accepted onto the waiting list, a person needs to be contactable 24 hours a day, seven days a week. Whilst on the waiting list people need to attend RPAH for regular blood tests. During this time, the hospital awaits a suitable donor organ. A liver donor has to be someone who has suffered brain death (eg, from a motor accident or a brain haemorrhage).

Preparation:

When a suitable donor has been found, a person is contacted and asked to immediately travel to the hospital. The person is advised to travel with one family member and must not eat or drink once they receive the phone call. Being called in to the hospital doesn't necessarily mean the operation will proceed. A person may make several such trips.

Surgery:

The transplant is very complicated and takes around eight hours. Removing the old liver can be extremely difficult, particularly if someone has had previous abdominal operations.

Transplants typically involve the severing and reconnecting of five vital structures: the major veins that drain into the heart, both above and below the liver; the vein that feeds food enriched blood from the intestines into the liver; the hepatic artery; and the bile duct, the major duct carrying bile from the liver to the intestine.

Rejection:

A person's immune system recognises the transplanted liver as foreign and will try to destroy it. Nearly all patients will experience one or more episodes of rejection and it most commonly occurs 7-10 days after surgery.

Doctors combat rejection by lowering the body's immune response through the use of anti-rejection drugs. For the rest of their lives, people remain on these drugs which, unfortunately, have significant side effects. This ongoing treatment involves a careful balancing act decreasing the immune response just enough to prevent rejection, but not so much that the body is in unnecessary danger of general health infections.

Because people are at an increased risk of general health infections (particularly in the first months following their transplant), care needs to be taken to avoid infections that most people take for granted. Things like: the flu, colds, cuts and grazes, cystitis, cold sores, etc.

Return of hepatitis:

After the transplant, hepatitis C usually returns (as does hepatitis B if a person has that virus). The hepatitis C does not usually cause problems for at least 5 years. Return of hepatitis B can be particularly severe and it's hoped that current experimental drugs can address this problem.

Emotional impact:

The operation involves considerable physical and emotional shock. It is a tense, anxious time for both patients and family alike. Along the way, there will be significant emotional distress connected with the operation itself as well as the drugs and medications involved.

- *Abridged from 'Information manual for liver transplant recipients & their families', Aust. National Liver Transplant Unit, 1996.*

While awake

My thoughts while awake
And my nightmares while asleep
Are all consumed by one thing
My chronic hep C

How long have I got, I think a lot
All alone
No where to turn
You feel so sick
And what do you get
But thoughts you're a freak

They make you think your pain's in your mind
Dear God believe me - I know what I feel
We need love
We need care

In my eyes
Life isn't fair
Help, help, I say to no avail
All I want is
to live one
more day
We've got
no life
We want
your help
to survive

by Lyn

(model used above)

Thanks HepCare

I'd like to take this opportunity to thank the Hep C Council for introducing me to Northern Sydney Area Health Service's hepatitis C healthcare trial - *'HepCare'*.

The introduction was done very professionally with an up front phone call asking me for my permission and my help. As a Managing Director of a very large publishing company it was nice that the in-depth survey didn't come out of the blue with an impersonal human being on the other end of the line. The questions that were asked were well thought out and mindful of my time; very much to the point.

An enormous amount of information must've been collected from respondents. It seems that finally someone's taken the reins and brought the buggy whip to bear on one of the most sensitive issues of our time. I'm confident that this valuable information will be collated and used as a model to improve the processes and procedures already in place to help present and future hep C sufferers alike.

Education in so many instances is the real catalyst to a better understanding of social problems like HCV. As a result of this collection of data I'm also mindful to be grateful for the creative structures that will be implemented. All of this helps me to deal with the physical and physiological issues of my illness in a pro-active and positive fashion.

Like so many of us with HCV I was angry, in denial and frustrated - quite happy to put the blame on someone else for woe was me. I've read so many stories of individuals who've felt the same emotions, but I've also read the other happier stories published in *The Hep C Review* as well.

Fortunately for me I have a positive disposition and because I'm generally a happy go lucky kind of guy and have a lot of friends who are genuinely supportive, did I mention as well my wife and a 10 week old daughter who love me dearly... I have so much to be thankful for. None of these people care that I have hep C in the sense that it or I present any risk to them, not one.

Yes, I am HCV positive. The questions I ask myself today aren't how long am I going to live? But instead, how am I going to improve my standard of health so that I live long enough to see my grand children?

The Hep C Review helps me to define that focal point and HepCare is allowing me and all of us who want to take control of our illness an opportunity to contribute to the model so that they can put check marks in place to bring about a better standard of care and understanding to people affected by HCV. Life is for the living and I intend to see it through until I'm old and grey.

Thanks *Hep C Review* for printing this and thanks to *HepCare* for demonstrating just how much you care. Isn't it true that organisations always tell us how much they care, yet rarely do they show it. You have. Keep up the good work!

Ron

TATTOOING and your health

Many people think that the hardest decisions about having tattoos done are the design and colour - and where the tattoo should go. WRONG! Because of the real risks of infectious diseases, including hepatitis C, the most important decisions are where and who you select to do the tattoo!

Most tattoo artists should know the potential risks to themselves and their clients of infections from contaminated, dirty equipment and surroundings. A professional artist practises good hygiene, follows infection control guidelines (such as sterilisation of equipment) and is happy to discuss with clients their shop's approach to customer health and safety.

Beware of backyard operators

The greatest risk for transmission of infections comes from operators who avoid the advice of tattooists associations or Local Government Authorities (local Councils). These operators may work from home or from unlicensed tattoo shops.

Backyard operators may not care about their professional reputation or business, and while they may charge a lot less than other tattooists, the risks of infection and poor work are greater.

Having tattoos done in prison carries a great risk of HCV infection or reinfection. If you're doing time inside, ask for information about the NSW prison tattoo project.

What to look for and what to ask

When you choose the studio where you think you might get your tattoo:

- look for clean hygienic premises, such as benches, sinks and other work areas;
- ask the tattooist if they use new needles each time - if they reuse needles, ask how they are sterilised;
- look for a certificate of accreditation from the local Council health department - it should be displayed prominently in the shop; and
- see if you can watch someone else being tattooed.

While watching, observe if:

- new disposable gloves are worn for each client;
- the tattooing equipment that's used comes from sterile containers or bags;
- they open pre-packaged sterile equipment in front of clients;
- they use small separate containers of ink for each client, instead of dipping into one big container that many clients would use; and
- the tattooist explains everything to the client.

Want more information?

For a copy of a brochure and booklet recently developed jointly, by the Professional Tattooing Association of Australia and the Commonwealth Department of Health & Family Services, phone the Better Health Centre (NSW Health) on 02 9391 9010.

For more information, also contact your local Council - their contact details will be in the White Pages phone book.

our very first readership survey

gives you a say in how our magazine looks and what articles it contains.

It will only take you about 15 minutes to fill out and we've provided a return paid envelope - see survey's fourth page.

We don't ask for your name or contact details anywhere. Most questions just require you to circle an answer. Others ask for your opinion. If you don't think a question relates to you, just leave it and go on to the next one.

WE'RE LOOKING FORWARD TO RECEIVING YOUR VALUABLE FEEDBACK!

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1. What is your age? (please circle one smaller number corresponding to your answer)

1 ..... under 20
2 ..... 20 - 29
3 ..... 30 - 39
4 ..... 40 - 49
5 ..... 50 plus

2. What's your gender? (please circle one small number)

1 ..... female
2 ..... male
3 ..... transgender

3. Where do you live ?

postcode _____

If outside Australia, which country

_____

4. What languages are spoken at home?
(please circle one or more numbers)

1 ..... English
2 ..... other (please describe)

_____

5. Where were you born ? (please circle one number)

00 ..... Australia / NZ
01 ..... Europe
02 ..... UK
03 ..... Nth America
04 ..... Sth America
05 ..... Middle East
06 ..... Sth East Asia
07 ..... Central Asia
08 ..... Africa
09 ..... Melanesia / Polynesia / Pacifica
10 ..... other (please describe)

_____

_____

6. Please describe yourself (please circle one or more numbers)

1 ..... person with HCV
2 ..... partner or family of someone with HCV
3 ..... friend of someone with HCV
4 ..... carer of someone with HCV
5 ..... healthcare worker
6 ..... social welfare worker
7 ..... other (please describe)

_____

_____

7. Are you a member of the Hepatitis C Council of NSW ?
(please circle one number)

1 ..... no
2 ..... yes

8. If yes, for how long have you been a member?

_____

9. If you have hepatitis C, have you ever had interferon treatment? (please circle one number)

1 ..... yes
2 ..... no

readership survey

10. If you have hepatitis C, have you used complementary therapies? (please circle one no.)

1 ..... no

2 ..... yes (please describe)

_____

_____

_____

11. My educational background is: (please circle the number next to the highest level you've attained)

1 ..... primary schooling

2 ..... some secondary

3 ..... school certificate

4 ..... higher school certificate

5 ..... college (TAFE, etc)

6 ..... trade certificate

7 ..... university

8 ..... post-graduate study

9 ..... other (please describe)

_____

_____

12. What is your usual type of occupation or work? (please circle one number)

00 ..... health professional - medical

01 ..... health professional - nursing

02 ..... allied health (eg. psychologist, AOD, social worker)

03 ..... other professional (eg. architect, solicitor, ADF, etc.)

04 ..... managerial / clerical / sales

06 ..... trades - skilled / semi skilled workers

07 ..... home duties

08 ..... student

09 ..... unemployed

10 ..... pensioner / benefit (please describe)

_____

11 ..... other (please describe)

_____

14. Do you find *The Hep C Review* easy to read and understand? (please circle one number)

1 ..... yes

2 ..... most of it

3 ..... some of it

4 ..... no

15. Which of the following features are of interest to you?
(for each feature, please circle one number from 1-4)

	1 *very interested always read*	2 *of mild interest sometimes read*	3 *little interest rarely read*	4 *no interest never read*
editorial	1	2	3	4
letters to the editor	1	2	3	4
news	1	2	3	4
information updates	1	2	3	4
focus of editions (see pg. 6)	1	2	3	4
personal stories	1	2	3	4
prevention page	1	2	3	4
interview	1	2	3	4
book reviews	1	2	3	4
regular info (see pgs. 36-38)	1	2	3	4
cartoons	1	2	3	4
use of photographs	1	2	3	4
use of other artwork	1	2	3	4

16. What do you think of our balance of features?
(for each feature, please circle one number from 1-4)

	1 *too much space*	2 *right amount of space*	3 *too little space*	4 *no interest no opinion*
editorial	1	2	3	4
letters to the editor	1	2	3	4
news	1	2	3	4
information updates	1	2	3	4
focus of editions (see pg. 6)	1	2	3	4
personal stories	1	2	3	4
prevention page	1	2	3	4
interview	1	2	3	4
book reviews	1	2	3	4
regular info (see pgs. 36-38)	1	2	3	4
cartoons	1	2	3	4
use of photographs	1	2	3	4
use of other artwork	1	2	3	4

17. Where do you usually get your copy of *The Hep C Review*?
(please circle one number)

1 ..... the Hep C Council posts it to me

2 ..... from a partner, friend or relative

3 ..... from my liver clinic

4 ..... from a needle exchange

5 ..... from a methadone provider

6 ..... other (please describe)

_____

18. If *The Hep C Review* were available on the internet, would you access it this way? (please circle one number)

1 ..... yes

2 ..... no

19. How many people usually read your copy of *The Hep C Review*? (please circle one number)

1 ..... just myself

2 ..... two in total

3 ..... three in total

4 ..... more than three (please describe)

_____

20. Do you like the name of our magazine - *The Hep C Review*? (please circle one number)

1 ..... yes

2 ..... it's okay

3 ..... no

21. Currently *The Hep C Review* is 40 pages long. Do you think it should (please circle one no.)

1 ..... be longer

2 ..... stay the same size

3 ..... be shorter

22. Can you suggest issues or topics that future editions could cover?

_____

_____

_____

_____

_____

23. What are your expectations of a magazine for people affected by HCV?

_____

_____

_____

_____

_____

24. What are your expectations of a magazine for those working with HCV?

_____

_____

_____

_____

_____

24. Do you think that *The Hep C Review* currently meets your expectations? (please circle one number)

1 ..... yes

2 ..... most of the time

3 ..... some of the time

4 ..... no

25. One aim of *The Hep C Review* is to reduce isolation and increase communication between people associated with hepatitis C. In regard to the range of people associated with hepatitis C, what do you understand by the term "hepatitis C community"?

_____

_____

_____

_____

26. Do you think the term "hepatitis C community" is a useful way of describing people affected by HCV? (please circle one no.)

1 ..... yes

2 ..... no

Do you have any comments?

_____

_____

_____

27 For which people is use of the term "hepatitis C community" most useful? (please circle one or more numbers)

1 ..... people affected by HCV

2 ..... healthcare workers

3 ..... politicians

4 ..... the media

5 ..... lobbyists

6 ..... other (please describe)

_____

_____

28. Was this survey easy to fill out? (please circle one number)

1 ..... yes

2 ..... no

Thank you for filling out our survey.

Please turn over for instructions on how to post it back to us.

Also overleaf you'll find space for additional comments if required.

To send ..

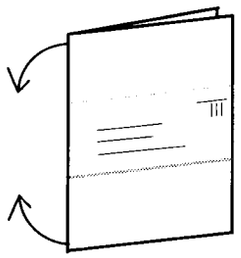
1 Gently pull out the centre spread survey form

2 Fold the bottom part of the page backwards

3 Fold the top part backwards

4 Seal the horizontal join with sticky tape (there's no need to seal the ends)

5 Post the survey form in your nearest post box.



Thanks again for your valuable assistance!

No postage stamp required
if posted in Australia

REPLY PAID No 618

PO BOX 432

DARLINGHURST NSW 2010

If you want to make any other comments, please print them clearly in this box.

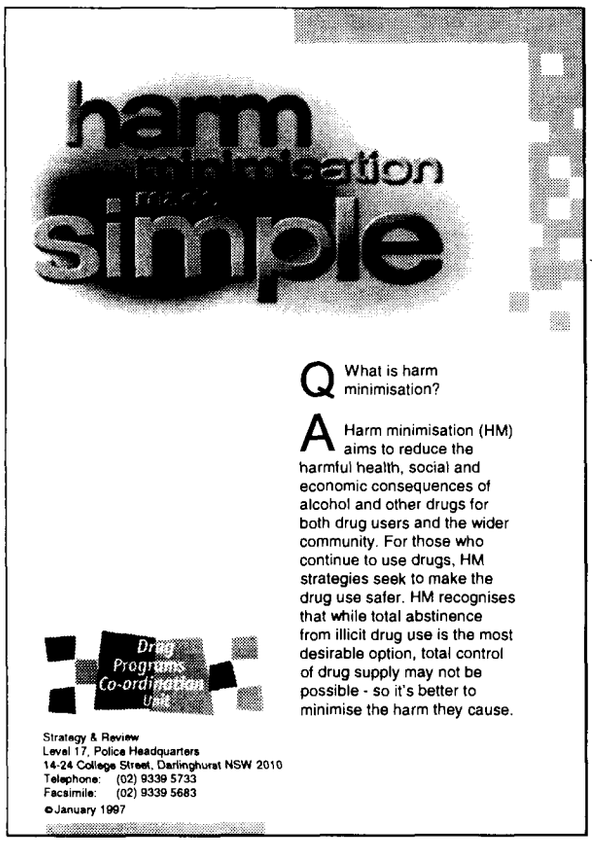
What is harm minimisation?

Harm minimisation (HM) aims to reduce the harmful health, social and economic consequences of alcohol and other drugs, both for people who use drugs and for the wider community.

For people who continue to use drugs, HM strategies seek to make the drug use safer. HM recognises that while total abstinence from illicit drug use is the most desirable option, total control of drug supply may not be possible - so it's necessary to also minimise the harm drugs cause.

Why is minimising the harmful effects of drugs the main goal of the National Drug Strategy?

Alcohol and drug use problems in Australia are estimated to cost more than $18 billion a year. This includes health care, loss of work productivity and law enforcement costs associated with alcohol-related road crashes and illicit drugs. Added to this are the dreadful consequences of family breakdown, crime, absenteeism, pain, suffering and death.



HM is an essential public health measure. Injecting drugs has been identified as one of the main behaviours at risk of transmitting hepatitis C virus and HIV.

Since the introduction of Needle Exchange Programs the number of diagnosed cases of HIV/AIDS has fallen and Australia now has one of the lowest rates of HIV/AIDS in the world amongst people who inject drugs. Similarly, needle exchange is believed to be helping cap the alarming rate of hepatitis C infection among people who inject. Support for programs which promote the health and safety of the community is an important part of drug law enforcement.

How does harm minimisation fit in with traditional drug law enforcement?

Drug law enforcement still concentrates on reducing the supply of illicit drugs available, in the hope that people will not take up or continue to use these drugs. Non-use is called total abstinence. However, research has now shown that the American-style "war on drugs" approach of the past has not achieved intended results.

The broader strategies of HM embrace many new areas such as police support for health protection measures, eg. Needle Exchange and Methadone Programs. Police Service Community Drug Education training courses are aimed at preventing the demand for drugs.

HM extends the range of traditional law enforcement and is achieving good results. For example, it has helped reduce the spread of HIV/AIDS.

How can police reduce the crime associated with drug use?

Rigorous police strategies are still in place to reduce the violence and crime associated with manufacturing, trafficking and dealing in illicit drugs. Increasing the number of chronic drug users who receive methadone treatment reduces their need for costly street drugs and therefore reduces property crime and crimes against the person. For some former illicit drug users, total abstinence can be an important part of this approach.

Why is police support for needle exchange and methadone units part of harm minimisation?

Because needle exchanges encourage safer health practices which have resulted in helping cap the incidence of hepatitis C and HIV; and methadone treatment means less crime in the long term because of a reduced need for illicit drugs.

- Abridged from the pamphlet: *Harm Minimisation made simple* produced by the Drug Programs Co-ordination Unit, NSW Police Service.

Naturally speaking

By Ses Salmond

Traditional Chinese Medicine

Professor Bob Batey and colleagues at John Hunter Hospital in Newcastle have conducted a 6 month randomised, controlled trial on 16 different Chinese plant extracts in the treatment of the HCV. Some of the herbs included were *Salvia miltiorrhiza, Paeonia lactiflora* and *Panax ginseng.*

CH100, the code name of the formula, has been developed by Cathay Herbal in conjunction with hepatologists in China. The trial involved 59 patients and no major adverse reactions have been reported. A tablet form of the herbs was used (not the usual Traditional Chinese Medicinal preparation).

Professor Batey (1996) wrote "there has been a fall in ALT in the patients on the active treatment. Six patients normalised their ALT during the treatment period. The percentage fall in ALT was 38% in the active group and 8.5% in the placebo group (p=0.048)".

Alcohol

Alcohol has been shown quite clearly to suppress the immune system and to allow viral replication to happen more actively than in non-drinkers who have HCV. Clinical manifestation of HCV is adversely affected by regular alcohol intake - ie. more than 1 drink per day.

HCV patients with ALTs around 150-200 while regularly consuming small amounts of alcohol, have liver enzymes which stabilise when alcohol consumption is discontinued.

With HCV it is important to cut down on alcohol consumption as much as possible, but extremely important not to binge drink. I have seen clients who have binged on alcohol (e.g. 8 spirits in one night) who ended up in hospital quite ill and with liver enzymes (ALT) over 2000.

"The most important factors influencing the speed with which [HCV] develops are alcohol intake and concurrent carriage of hepatitis B." (Crofts 1994)

"There is evidence that alcohol and hepatitis C may synergistically aggravate hepatic injury." (Dusheiko et al. 1996)

HCV damage

Before addressing the medicinal actions of herbs required in the treatment of HCV it is important to understand more about how HCV causes disease - especially, how HCV may cause the body's immune system to damage liver cells (autoimmune damage). Liver cell injury due to HCV infection is not fully understood. Evidence of both cell damage caused directly by the virus, and injury caused by the body's immune system have been discovered.

Autoimmune liver damage is suggested by the frequent finding within the liver's portal tracts, of lymph follicles which contain particular types of white blood cells. In addition auto-antibodies are frequently found in people with HCV infection, suggesting that our immune system may cause disease. T-cell responses that cause cell damage have also been demonstrated (Jonas 1996).

Jonas also suggests that a possible mechanism implicated in disease caused by chronic HCV, is the infection with more than one HCV genotype.

According to Batchelder and Hudson (1995) the following treatment principles are important in viral hepatitis:

- Boost the immune system
- Prevent cell damage, and encourage cell regeneration
- Promote bile flow, waste elimination and detoxification
- Address addictions (eg. alcohol)

The use of herbs in the treatment of viral hepatitis offers tissue support, the prevention of cell damage, and alternative pathways to avoid inflammation. Particular substances within herbs, such as silymarin from the milk thistle plant, have demonstrated an ability to help prevent viruses reproduce, provide a boost and support to the immune system, and to help regenerate liver cells (Batchelder and Hudson 1995).

A clinical observation I have made is that the addition of herbal antioxidants to the herbal mixtures has a marked effect in lowering liver enzymes and improving liver function.

- Ses Salmond is a practising naturopath at Leichhardt Women's Health Centre.

NEXT EDITION

The focus of our next edition will be on legal issues connected to HCV.

Please write in with any HCV legal questions you'd like answered - or send us your personal story.

Examples of questions might include:

If I've got HCV, can I use IVF?

Would I have to disclose my HCV when I take out a home loan?

Helping the helpers

An interview with Mark McPherson, manager of CEIDA's Professional Development Unit.

A lot of readers will be wondering what CEIDA is, and what the Professional Development Unit does. Can you explain this Mark?

CEIDA is the Centre for Education and Information on Drugs and Alcohol, based in the Rozelle Hospital grounds, here in Sydney.

Typically, we're seen as providers of training programs for healthcare workers across the state, and the place people can contact for information on alcohol and other drugs.

The Professional Development Unit is taking training for workers in alcohol and other drug use one step further. We recently posed the question, "Is the provision of training to individual workers an effective way of improving healthcare services?"

Speaking to the many people involved in training networks within Area Health Services across NSW, it became clear there needed to be more. A different way of working was seen as necessary to ensure that following training, the added skills and knowledge of healthcare workers actually resulted in better healthcare programs.

It was seen that there were specific skills and knowledge necessary for the effective development, design, implementation, and evaluation of programs related to prevention and treatment.

So not only do we deliver training programs for individual workers, increasingly, we deliver a range of programs for Area Health Services and other organisations wanting to build and sustain their capacity to build effective healthcare programs.

Can you explain to readers what Area Health Services are?

NSW is divided up into 17 Area Health Services, each one being responsible for delivering healthcare services in a particular region of the state. It's a similar system to that of local government - ie. local City and Shire Councils.

Found in each Area Health Service, is a CEIDA contact. Within their normal day to day work, these people also act as a liaison point for feedback and other ideas about our courses and our overall approach.

Do you run specific courses covering hepatitis C?

Within CEIDA's Professional Development calendar, we have courses focussing on HIV and viral hepatitis which cover latest clinical and epidemiological research, testing, treatments, local and state-wide services, and a range of other topics including explorations of issues around confidentiality and discrimination.

What brought you to this field, Mark?

A long winding road! Years ago as a science/geography school teacher, I steered myself towards health studies and after additional studies, I took up a position in Teacher Education. I followed this with a position at Family Planning. After stints at TAFE and the NSW Board of Studies, I worked in Health Promotion at Central Sydney Area Health Service, before taking up a position working as the HIV/AIDS Coordinator within the South West Sydney Area Health Service. With six years experience in HIV/AIDS, I then took up my current position at CEIDA.

What challenges do you face in this position?

As a manager, my biggest challenge is to juggle the needs and desires of NSW Health, Area Health Services, CEIDA, workmates, healthcare workers, people with hepatitis C and the general community. All of these responsibilities exist within a context of internal change here at CEIDA - from a straight training organisation to one of 'capacity building'.

- For information on the CEIDA Professional Development Unit, phone 02 9818 0434. For information on your local CEIDA Area Health Service contact, phone your Infectious Diseases Coordinator, see page 38.

Who I Am

Like many people with chronic, life-altering diseases, I've thought often about my illness in relationship to my life. I've wondered whether or not there is a purpose and whether or not to fight or give up.

At times when I felt alone, helpless and sick - too sick to get out of bed sometimes - I've tried to think about what I could possibly do to help others and in the end maybe help myself as well.

Sometimes it seems some must suffer in order for others to learn and make things better for people coming up behind us. And even though this may sound grandiose, I must either believe it or I must give up. I've decided to believe it.

I was transfused with two units of blood after an emergency caesarean section in 1981. Within a few months I came down with hepatitis B from which I recovered and went on with my life. In 1987, I began feeling tired but tried to ignore it.

Then in 1989, after my two years of tiredness had turned into total exhaustion, I became so ill I had to quit working outside of my home. I was literally home bound and it was during this period that blood tests finally confirmed I had hepatitis C.

Very little was known about this disease which affected me so severely. I had a family to raise and I decided that if they couldn't figure out what was wrong with me, then I'd better figure it out myself.

So I started studying medicine from my bed. Nine years later, I'm still studying and keeping up with the most current research, discoveries and treatments. I've also studied human anatomy, biology and general medicine - as well as the speciality areas of gastroenterology, the immune system, the endocrine system, psychiatry and how they interrelate.

But I found out right away that when I walked into a doctor's office armed with knowledge I'd found on this subject or that subject I was often discouraged from reading since I might "misinterpret" what I'd read. "Best leave that up to the experts," they would say. I kept studying anyway but stopped telling them I knew anything.

I do have one fond memory of my first meeting with a doctor who I finally went to see during a period of such severe illness that I needed help walking and had to ride around the clinic in a wheelchair.

I was still in my "militant" days and went into his office armed with medical literature I'd copied ready to "prove" to him why I was right about my opinions. The literature I'd chosen to copy I felt had been written by someone who obviously knew what he was talking about. It backed up everything my opinions had been formed around.

I presented my copies to this doctor and he chuckled and said, "Oh yes, I wrote this."

And then he said "You like to read? Here's some more stuff," and began handing me more and more abstracts from other research papers he'd published. He immediately got my total respect and trust. This doctor also had a special gift that I'd seen in few other doctors. He could see the importance of taking care of his patients as human beings and not seeing them as just cases.

Because he worked with me, validating my symptoms as being real - and not "in my head" - I feel he literally saved my life.

Love - Liz

- *A personal story taken from the internet. Liz, pictured above, probably lives in the USA or Canada.*

"LOOK BACK LOOK FORWARD"

By Kathy Sport

I'd like to thank all those people who phoned to inquire about my video project. Some of you may have seen the advertisement for participants in last February's *Hep C Review*.

I received an overwhelming number of calls which meant I was not always able to return messages. However I was extremely encouraged that so many people were prepared to speak openly about very personal matters. Congratulations to those who finally faced the camera. Sharing your moments forever required much bravery and strength.

I am a recent film major graduate from the University of Technology Sydney, BA Communications. I am also HCV positive, as are several of my friends. The idea for the video came in mid 1996 when I watched a television current affairs story about HCV. The story seemed to promote sensationalism and scaremongering rather than education and prevention. My own older, worried parents watched the program and became even more worried - enough said. I felt that if those living with HCV had a voice that could be heard as well then a less sensational understanding of the virus might be achieved and some of the myths dispelled.

Look Back Look Forward became my final year film project toward my degree. I approached the Hepatitis C Council for help and guidance to put the idea into action. Eight months down the track the half hour documentary is finished, complete with one happy filmmaker who is very excited about this video and who has been filled with encouragement that there are ways and means to get things done.

A scene taken from the soon to be released video, "Look back, look forward", produced by independent film maker Kathy Sport

The first stumbling block was realising limitations and that the project could not possibly cover every aspect of HCV. As the project developed, three issues increasingly came into focus:

a) coming to terms with the virus,

b) choosing a treatment pathway, then

c) managing life with a long term chronic illness.

Of the many people I talked to, some had experienced direct discrimination from those with the most power to hurt deeply - family members. Others had a fabulously supportive environment. Some had no viral symptoms at all - others extremely poor health with life threatening symptoms. Common to most was the need to feel less isolated, but above all was the desire to be accepted and to get on with life.

Shot on digital video (mini DV) with a tighter than tight budget and a small unpaid but dedicated crew, *Look Back Look Forward* is light and positive without steering away from HCV's difficult issues. Four people currently living with the virus are interviewed and as they speak, the process of how individuals confront a major health crisis differently is gradually revealed (thanks go particularly to Kelvin for the belly laughs).

Inter-cutting these stories are interviews with three workers. Professor Bob Batey, Helen Mann and Peter de Ruyter represent a cross section of support services ranging from interferon to counselling to alternative therapies.

Who would be interested in seeing this film? I believe the film has three main audiences - those with HCV, those working in the field of providing healthcare and information services, both professionally and non-professionally, and lastly, friends and family.

Look Back Look Forward is suitable for general, individual or group viewing and discussion. It is particularly appropriate for training and support group use and would also be of benefit in correctional services settings. When things are too hard to say yourself, especially in personal relationship situations, it's sometimes handy to have another form of communication to start the discussion.

This project has taken me on a priceless personal and professional journey I will never forget. Thanks again to those people who let me into their lounge rooms and kitchens and to those who just wanted a chin wag on the phone. My own hep virus no longer has killer monster proportions.

Kathy Sport

- Look Back Look Forward *will soon be available through the Hepatitis C Council, once funding for final production processes is finalised. WATCH OUT FOR ADVERTS FOR THE BIG SCREEN LAUNCH.*

Biopsy - the inside story

Abridged with assistance of Geoff McCaughan from an original article by Graeme Macdonald in 'Hep C News' - the regular newsletter of the Hepatitis C Council of QLD (07 3229 9238).

Why do a liver biopsy? Can't you get enough information from blood tests?

When a person might have liver disease their doctor will use a variety of means to determine the level of possible disease. These methods include assessing the severity of symptoms, blood tests, ultrasound (or other x-rays of the liver) and liver biopsy. Each of these provides different information. Together, they can be used to evaluate the impact of hepatitis C on a person's health, the risk of complications in the future and to optimise management of their illness.

An person's symptoms are important because they indicate how the hepatitis C is affecting their life. However there is little correlation between the severity of symptoms and the extent of liver damage.

One of the main blood tests performed is an ALT measurement; however, the ALT level is an indirect measure of liver injury and doesn't always reflect what is happening in the liver. Most importantly, the ALT level cannot indicate if a patient has cirrhosis or not. Some patients can develop significant liver damage even though their ALT is in the normal range - however this is less common than when liver damage coincides with elevated ALT levels.

Ultrasound and other X-rays can indicate if there is a blockage of blood vessels to or from the liver, if there is an unusual mass in the liver such as a tumour, and can suggest that a patient might have advanced cirrhosis - however, the 'might' must be stressed. One of the problems with these X-ray techniques is that they have difficulty distinguishing cirrhosis from other conditions such as fat accumulation in the liver. This is particularly true in early cirrhosis, before scar tissue has affected the outline of the liver and blood flow in the main vein that carries blood from the intestine to the liver. The diagnosis of cirrhosis can only really be made by liver biopsy.

Why make such a big deal about cirrhosis?

Because the diagnosis of cirrhosis has implications for a person's future health and the likelihood of responding to treatment for hepatitis C. In Australia, the diagnosis of cirrhosis also affects whether people can receive government-funded interferon under the section 100 (S100) scheme.

Cirrhosis can be caused by many different liver diseases, however in Australia the most common causes are excess alcohol and hepatitis C infection. A diagnosis of cirrhosis means that liver injury has lead to the build up of fibrous scar tissue in the liver to such an extent that the microscopic structure or "architecture" is affected. This scar tissue affects the blood flow through the liver and the function of the cells in the liver. Because the scar tissue affects the microscopic structure of the liver it, can only really be diagnosed by looking at a tiny piece of liver tissue down the microscope.

It has been estimated that between 20% and 30% of people with HCV and ongoing significant hepatitis may develop cirrhosis after 20 to 30 years of infection. A diagnosis of cirrhosis is an important event for people because it means that they are now at increased risk of developing liver failure, primary liver cancer and other complications of cirrhosis. Because of the increased risk of these complications, people with cirrhosis may undergo testing and increased surveillance for these complications, so that hopefully they can be treated before they become life-threatening.

Unfortunately, people with cirrhosis are less likely to respond to interferon therapy. Their response rate to this treatment is only about half that of those who do not have cirrhosis. This appears to be the reason that the government currently does not fund interferon therapy under the S100 scheme for people with cirrhosis.

The presence or absence of cirrhosis is only part of the information available from liver biopsy. Apart from showing the amount of scar tissue (an indication of what has happened to the liver in the past), liver biopsies also show how active the hepatitis C is now, and if there are other factors interacting with the hepatitis C to damage the liver. These other factors include things like excess alcohol, iron accumulation in the liver or evidence that the body's own immune system is attacking liver cells (autoimmune disease).

A pleasant surprise?

A liver biopsy should also be considered for reassurance of a person's prognosis. As mentioned above, progression to cirrhosis is not by any means inevitable and a biopsy after 20-30 years of infection may still

show mild changes. Such a finding can usually be reassuring to a person as it is likely (though not proven) that such people have 'selected themselves out' and may be in a sub-group that may never progress to serious liver damage. A biopsy for these reasons should really only be done if someone is anxious and fully aware of the issues discussed above and below.

But because a liver biopsy is only a tiny bit of the liver, is it an accurate guide to what is happening in the whole liver?

A liver biopsy is representative of changes throughout the liver due to hepatitis C. Hepatitis C affects the whole liver and although there may be some variation within the liver, this would be a minor rather than major variation.

Is a liver biopsy painful?

There are actually several different types of liver biopsy, but the type most people have is called a *percutaneous needle liver biopsy*. 'Percutaneous' means it is performed through the skin, usually between the ribs on the right side of the abdomen. 'Needle' describes the biopsy device and although there are several types, they are all basically needles.

Local anaesthetic is used to numb the skin and liver prior to the biopsy. Injecting the local anaesthetic can take a couple of minutes or longer. Some doctors also give an intravenous injection to help patients relax. The actual biopsy usually takes about one second. People usually remain at hospital after the biopsy for at least 6 hours or even overnight.

It is not usually painful at the time of the biopsy although some people do have a sensation of pressure in their abdomen. About one in ten people will have significant pain after the procedure that requires an injection. This pain usually only lasts 20 to 30 minutes and responds to the injection.

Is a liver biopsy dangerous?

Only about 1 in every 300 people who have a liver biopsy could have a serious complication such as bleeding from the surface of the liver. This would usually mean staying in hospital for a day or two and may require an operation, although this is rare.

Only about 1 in every 1000 people who have a liver biopsy could die from it. So yes, there are risks with a liver biopsy but these risks need to be balanced against the benefits of more precise knowledge of what is happening in the liver.

Liver biopsies are not recommended lightly. Because of the relatively low, but none the less real risk associated, the final decision to proceed with biopsy should be made by the individual person.

How does my doctor make sense of my biopsy result?

A doctor will usually explore 2 major issues in looking at the liver biopsy.

Firstly, are the features consistent with HCV as the cause of the liver test abnormalities? i.e. are there other pathologies present?

Secondly, if the biopsy is consistent or diagnostic of HCV, then how badly is the liver damaged? This can be estimated by studying 3 main parameters:

(a) The amount of portal inflammation - which is the inflammation around liver cells, bile ducts and veins in parts of the liver.

(b) The amount of lobular inflammation - which is the amount of inflammation in the liver lobule itself.

(c) The amount of fibrosis - which is an early stage in the development of liver cell scarring (cirrhosis).

These 3 features may be given scores of 0-4, where 4 is the worst scenario. Thus the overall biopsy may be scored out of 12. The first two (inflammation) are often called the *grade* of HCV whilst fibrosis may be referred to as the *stage* of HCV.

It is the latter that can give an idea to the chances of progression to cirrhosis over the next 10 years or so. Stage 4 hepatitis C (a fibrosis score of 4) is already cirrhosis, whilst a stage of 1 may only progress to stage 2 over 10-20 years.

Others aspects of the biopsy such as fat and biliary inflammation are only sometimes present and do not seem to influence outlook. Apart from data regarding prognosis the overall response to therapies such as interferon can be predicted from biopsies. People with stage 3 or 4 fibrosis tend to respond poorly to interferon - however it is these people who may need it the most!

- *Graeme Macdonald is a consultant gastroenterologist at the Royal Brisbane Hospital.*

  Geoff McCaughan is Director of the AW Morrow Liver Centre and Physician in Charge at the Australian National Liver Transplant Unit.

Access to viral testing in hep C treatment

In a disappointing move, the Australian Health Technology Advisory Committee (AHTAC) recently recommended that *"evidence on the value of [PCR] for monitoring HCV progression is unclear and further evaluation and monitoring are required".*

The ongoing development and use of PCR testing technology is a rapidly evolving field. So rapid are these developments that judgements and decisions, however reasonable, can quickly become irrelevant and outdated.

Many people see the above AHTAC recommendation as outdated. They believe that, if adopted, people with hepatitis C will be denied access to PCR testing (for monitoring treatment) probably for at least two years.

Our national HCV advisory body, the Australian National Council on AIDS and Related Diseases (ANCARD) has been monitoring this situation. The Clinical Treatments and Trials Advisory Committee - an ANCARD's sub-committee - has quickly begun a response and drafted a submission countering the AHTAC report.

The submission draws evidence from over 70 studies world-wide and calls for:

- HCV viral load testing and HCV genotype testing for predicting treatment outcome,
- HCV viral load testing for monitoring treatment (during and afterwards).

Also included in the comprehensive submission is a discussion on the economic cost-effectiveness of wider access to PCR and related tests.

A binding government decision will soon be made on our access to these tests. It's quite possible people with HCV will be unfairly denied access to them. If you are concerned about this, please phone or write to your local Member of Federal Parliament, or to the Federal Minister for Health, Dr Michael Wooldridge.

To get contact details for your local member, contact the Australian Federal Electoral Commission by phoning 13 2326.

Or write to: The Hon Dr Michael Wooldridge
Suite MG48
Parliament House
CANBERRA ACT 2600

Ribavirin explained

People are beginning to take a real interest in ribavirin. Given the news coming out of the Chicago Conference, it's easy to see why (page 10). But what actually is ribavirin?

Ribavirin is an anti-viral drug used for years in treating bronchiolitis - a respiratory condition of babies. It's classified as a *guanosine analogue* drug that disrupts viral activity by confusing the virus's assimilation of genetic material during replication.

For viral hepatitis, the drug is taken in tablet form. It's not habit forming but certainly requires prescription. Accidental overdose is unlikely to threaten life but is serious enough to necessitate a call to the poisons centre.

Side effects or adverse reactions can include tiredness or weakness, headache, insomnia, appetite loss or nausea. Rare side effects include skin irritations or rashes.

There are two major concerns with ribavirin when used for hepatitis C. It can cause anaemia (low red blood cell count) which is occasionally severe - also, ribavirin has caused birth defects in trial animals.

Thus, ribavirin must not be prescribed for pregnant women or those currently breast feeding, or for couples not taking contraceptive precautions during and for several months following treatment.

When people discontinue ribavirin, a gradual reduction of medication is recommended when the treatment has been taken for any length of time. Doses of other drugs may also require adjustment.

Ribavirin interacts with zidovudine and causes the decreased effect of both drugs. It is not believed to interact with alcohol, other beverages, foods or tobacco.

The treatment is likely to be very expensive - it could add four times the cost of interferon alone to the overall cost of HCV treatment. It's important to note that ribavirin is not yet licensed for use with hepatitis C in Australia. Availability here is therefore limited - the drug is more widely used in Europe.

Ribavirin alone is not effective for hepatitis C, but, combined with interferon, is promising. Currently, people interested in trying ribavirin would be limited to accessing it through the existing co-treatment trial just begun by the Hepatology Section of the Gastroenterological Society of Australia - a trial aimed at previous interferon non-responders.

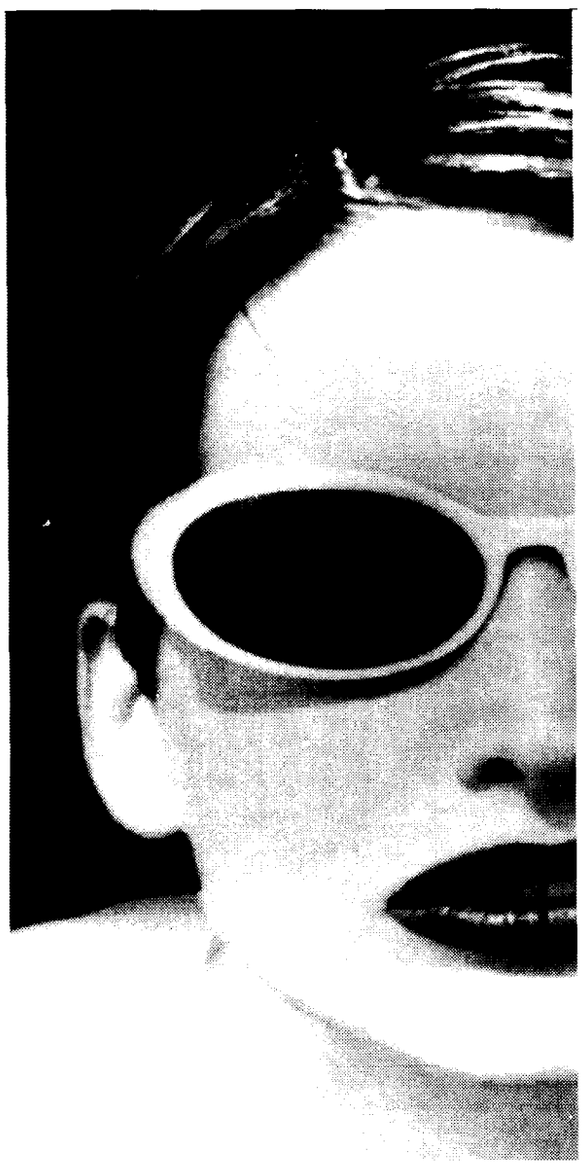
New trials will be designed for interferon relapsers and people who have not previously received interferon treatment. We'll pass on more information on these trials as it comes to hand.

Why can't you play, Mummy?

My name is Lisa, I'm 32 yrs old, I'm a wife, I'm a mother of three, and I have hep C. When I found out I had HCV in June 1994, I was devastated, though, in reality I shouldn't have been surprised. For many years I had put myself in "high risk" positions.

While nursing I suffered a couple of needle sticks; I had a tattoo; I had unprotected sex and I had shared syringes. All are equal to playing Russian roulette but since I had regular blood tests which all came back negative - I took pride in myself that I was a "clean" junkie. Which is why I was surprised when 3 yrs after my last "shot" I was suddenly told I had HCV.

My husband went straight to the doctor for a blood test which came back negative. This surprised our doctor as well as us, as we both thought he would test positive also. My boys were also negative.



Anyway once the original shock wore off I started asking questions. I soon found out how little is commonly known about hep C. Some of the fantasies I heard were:

- 90% of junkies have Hep C. So it's nothing to worry about.
- HCV can be passed on by breathing, kissing, using my toothbrush or comb, using my cups etc.
- My husband and children must have it.
- Only junkies or/and prostitutes have it.

I really couldn't believe how naive most people are about hepatitis in general. I was totally shocked to find such ignorance around professional people such as dentists, chemists, police, and even some doctors and nurses took precaution to the extreme.

Some people have told me, it's my own fault for telling others - but I believe I have a responsibility to tell anyone who may be put at risk by me, eg. ambulance officers, doctors, dentists, etc.

In August 1996 after 2 years of monthly LFTs (liver function tests) and a couple of liver biopsies, I was finally put on the Interferon programme at Westmead. Every two months I would make the 6 hour drive to Westmead to pick up my supply of medication and syringes etc, and I continued with fortnightly LFTs.

The change in my health was amazing. By the way I had no side effects at all! Several weeks after I started the programme I noticed how much better I felt - and I just got better and better.

Finally I had energy again. I could play with my children, do the housework, gardening etc. Most of my aches and pains were gone; the nausea which I had lived with for years stopped. I felt alive again - as though I had been given a second chance; I was so sure that the interferon was working.

Then - my life was shattered again. Westmead told me they were taking me off the programme for lack of improvement.

I felt like someone had cut off my air supply; I couldn't go back to being sick again - it wasn't right; not when I knew how well I was doing - my family and friends couldn't understand why either.

Now 8 months after being cut off the programme, my life is back to "normal" for me. I wake up every morning with permanent "morning sickness". Some days just getting out of bed is impossible.

My little boys ask me "When will you be better again Mummy?", "Why can't you play, Mummy?", "You're always too tired", "It's not fair". And they're right - it's not fair - not for my children or for my husband - who has a wife that can barely do her home duties, never mind her wife "duties".

And it feels even more unfair knowing that there is a medication to help me, yet I can't get it - once you've been on Interferon there is no second chance. In the area I live in there is no support for hep C people at all. My local doctor admits he knows very little about the virus and the Community Health Centre has no support group or even a counsellor. Most of the time I feel alone, isolated and sick. Sick of being sick, sick of people's ignorance, prejudice and paranoia.

Anyway, I just wanted my say. Thank you for taking the time to read this letter,

Yours sincerely - Lisa

(model used left) ←

Clinical Hepatology Research Nurses Association of NSW & ACT

NOTICEBOARD

Our guest speaker at the next CHRNA (NSW) meeting will be Public Health Officer, Kerry Todd, from the Hunter Public Health Unit.

Kerry will discuss epidemiological patterns and issues relating to HCV.

All healthcare workers associated with HCV are welcomed to our next meeting:

Conference Rooms, Level 3 at John Hunter Hospital, Newcastle (Lookout Rd, New Lambton)

Friday, 13 February 1998, starting 6pm.

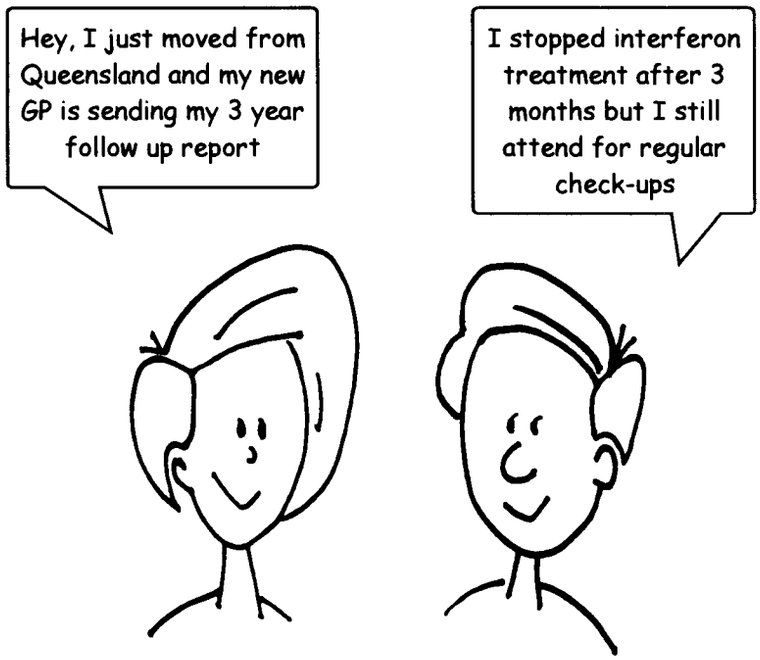
For more information, please don't hesitate to contact:

Tracey Jones (John Hunter Hospital)

02 4921 4789 or

Sue Huntley (Concord Repatriation Hospital)

02 9767 5000.



If you've had interferon and don't attend for follow up checks, they won't find out how to improve the treatment. Make sure your treatment centre or GP forward your follow up reports to the Hepatitis C National Database
ph. 02 4921 7431 fx. 02 4921 7432

'SPACE FOR RENT'

If you're a hepatitis C service provider and want to advertise within the Hep C Review, please contact Paul on 9332 1853 for more information.

The magazine is posted to over 2,000 readers from a variety of backgrounds. They include people affected by HCV, Area Health Services CEOs, public health workers, HCV clinicians, GPs, liver clinic staff, needle exchange and methadone workers, health planners.

Special thanks to EMAIL, manufacturers of quality white goods, who recently generously provided a new fridge for the Council.

SPAN
SOUTH PACIFIC AND ASIA NETWORK
healthy & happy

SPAN's web site, *HEALTHY & HAPPY* aims at promoting information networking within the Asia-Pacific region, and can be found at: **http://www.span.com.au**

Within SPAN, the Hepatitis C Council has a web page at:
http://www.span.com.au/hepatitis_c/info.html

Our site contains general information taken from *Hepatitis C: what you need to know*, and will soon feature the Council's new graphics.

Have you had S100 interferon?

Almost 3,000 hepatitis C patients have now received interferon under the Federal Section 100 (S100) scheme.

S100 involves a five year monitoring process to help understand the natural history of the disease in Australia. Results have been stored anonymously with the Hep C National Database (NDB) since October 1994.

The S100 experience differs from major clinical drug trials in that a broader cross-section of the Australian community is represented and results of all patients continue to be recorded, regardless of treatment outcome.

With 67 treatment centres across the country, and nearly 3,000 patients being followed, the task of compiling complete information is enormous. If you have received any amount of interferon through the S100 scheme, your follow up information is vital.

Where do you fit in?

Whether you responded to treatment or not, or had to cease treatment early, your results are of major importance to this exercise. The critical follow-up points are as follows:

- every month while on treatment
- every three months for one year after treatment has finished
- then on a yearly basis thereafter.

How do you get your results to the NDB?

Keep in contact with your treatment centre or GP. They will keep you in touch with new treatment developments. They can arrange for your blood tests to be done at the appropriate times and will send the results through to the NDB. All information is de-identified.

Your cooperation will ensure the success of this exercise. You will be helping to build an invaluable resource of information aimed at improving the management of this disease and determining future directions of the treatment of hepatitis C in Australia.

Dear Healthcare provider ..

I was alarmed at the treatment my husband "Emmanuel" received while attending your pathology service recently.

One of your employees after looking at Emmanuel's pathology request, said "what have you got?"

To this my husband answered "hepatitis C". Emmanuel was then shocked when rudely asked, "where'd you catch that?"

Not wanting to cause problems, Emmanuel answered, "from a tattoo several years ago."

Your employee then started preaching to my husband, saying, "you know that is a highly contagious disease and you can spread it to your kids, family and friends just by drinking out of the same cup."

Emmanuel, who has been to several specialists and who is currently on the interferon program, was shocked and replied, "no - it's only transferable by blood."

But your employee kept persisting, "Oh, that's just what the doctors tell you. It's not right! I know all about it and it is contagious."

My husband has suffered a lot of anxiety and stress over the past year and a half due to this illness and is on weekly medication. He does not need to feel pressure and be made uncomfortable by a person who is supposed to be a trained healthcare worker.

This is how rumours and discrimination start off - by ignorant people shooting their mouths off.

I hope to get a written apology from your company for this unacceptable behaviour and treatment.

Sincerely - Frances

(model used above)

A comment on diet & HCV

By Peter de Ruyter

From a naturopathic perspective, a major point I'd like to raise is that diet cannot be divorced from other inter-related factors. It is vitally important not just to discuss the correct foods for a patient with hepatitis C, but to ensure such a diet is seen within the context of an optimally functioning gastrointestinal tract. In a sense, health is not so much dependent on what one eats as what gets *absorbed* of what one eats.

Controversial as it may be, there is sufficient medical data to show a clear correlation between the health of the gastrointestinal system and subsequent liver function, through the mechanism of "the leaky gut syndrome."

The aim of any specific diet for hepatitis C should therefore take into account not just nutrient value, but also its ability to repair and maintain adequate health of the gut, especially the mucous and immunologically active lymphoid tissue so prevalent in this vast intestinal organ.

One perhaps ludicrously simple - yet inevitably under-utilised technique of improving digestive function, is to encourage proper chewing of food and to only eat under restful conditions.

Too often, people in our stressed-out culture will bolt their food down. This does affect the next stage of digestion in the stomach and in turn, absorption of nutrients later in the digestive process.

On the other hand, eating under restful conditions maximises parasympathetic nervous system function and thereby also maximises nutrient digestion and absorption. Obviously important in any situation where the body is chronically fighting an infection.

Such low-tech approaches are too often forgotten or ignored in dietary advice. Yet they cost nothing, are ridiculously simple and highly effective techniques of enhancing nutrition.

We, as natural therapists, see gastrointestinal health as directly implicated in how much stress - through toxicity - the liver has to contend with and we would focus a lot on foods which keep the gut as healthy and functional as possible.

• **Peter de Ruyter is a practising naturopath at Bondi Junction Wholistic Medical & Yoga Centre**

Just what the doctor ordered

My story relates to complementary therapies. I was diagnosed with hepatitis C in June 1997. My doctor suggested that I try the Cathay Herbal laboratory CH-100 liver tonic.

I remained on on these tablets for two months (costing $92 a month). I was withdrawn from this treatment, though, as my LFTs doubled.

My doctor then sent me to a Chinese doctor who practised both western and Chinese medicine. I had some acupuncture, but I developed a strong aversion to the needles.

I was also prescribed some other Chinese pills, called Long Dan Xie Gan Wan, at a cost of $3.50 for 200 pills.

After a month of taking these pills, I have felt significantly better. I had been ill for 18 months with the severe fatigue and mental lassitude attributed to CMV (Cytomegelo virus - similar to glandular fever) aggravated by two courses of the liver toxic antibiotic, Flucloxocyllin.

With Chinese medicine, you need an individual diagnosis. What worked for me may not work for others.

My doctor has also prescribed a Vitamin A & C powder to keep my immune system 'on top of things'. (This was not the same doctor who prescribed the antibiotics, just mentioned.)

xx (unsigned)

Chrissy's story

My story is not about having hepatitis C but being the partner of someone who does.

My husband has had the virus for about 20 years or more due to his old drug days. I do not have the virus but I'd like to share some of my fears hoping that other partners will share theirs. We partners have to deal with the virus also, as much as our positive partners only in a much different way.

We are all aware of the ways to contract HCV and my partner refuses to wear a condom. This brings me to my fear and makes me ask the question: "Does anybody really know for sure that HCV cannot be transmitted by sex?"

"The statistics tell us that it's a 'low' chance, and that this may be 1%. But really, who knows for sure?"

I watch my husband suffer, sleeping his days away. I feel his frustration and wear his anger and moods. He cannot work and I maintain house duties, manage part-time work, and we have a beautiful 10 year old daughter. Our aim is to both watch her grow up.

I love my husband very much and will continue to have unprotected sex even if sometimes I feel it's against my better judgement.

I'd like to hear from anyone who has contracted HCV through sex or anyone who just wants to share their story as us partners need caring, supporting and reassuring as well.

Love Chrissy.

(models used above)

Dear Chrissy

There is still a lot to be learned about the hep C virus and I understand your concern about sexual transmission.

Early studies of people who had acute hep C or a high risk of exposure to sexually transmissible viral infections supported a role for sexual transmission of HCV.

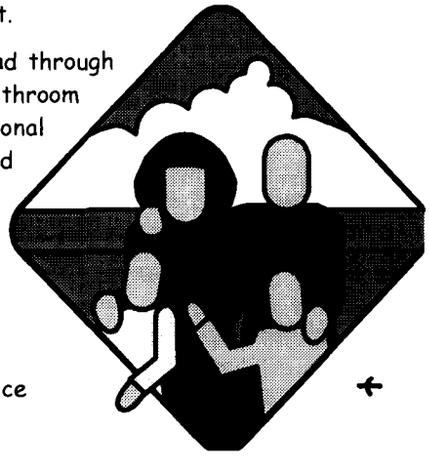
However, more recent studies in Western populations that have involved the direct testing of partners of people with HCV have demonstrated negligible or no transmission.

At the Australian Red Cross Blood Service-Sydney, I have routinely offered testing to the current partner of blood donors found to be hep C carriers - the few partners who have tested positive have had an alternative risk factor.

You and your husband's circumstances are similar to those of most of the couples I have counselled. You have been in a relationship for at least 10 years and your husband's exposure was likely to have been 20 years ago. Despite unprotected sex, you have not been infected.

I advise couples in long-term monogamous relationships that it is probably unnecessary to modify their sexual practices, other than to consider using condoms during menstruation, anal intercourse or when genital ulceration is present.

However, as hep C can be spread through direct blood contact, "safer" bathroom practices - not sharing personal items such as razor blades and toothbrushes - are always recommended.



Best wishes

Andrew Davis
Medical Officer
Australian Red Cross Blood Service

Thanks everyone

In the last edition, we posted you survey forms relating to diet and evaluation of our booklet *Hepatitis C: what you need to know*. We received over 400 responses which was really AMAZING!

A small group of people are now working hard initially on an HCV & diet factsheet, and then on a comprehensive booklet on diet and hepatitis C.

Your generous feedback was very important in steering our project and we hope you'll appreciate our finished products. The factsheet should be finished around May '98.

Because it's much more detailed, the diet booklet probably won't be ready until much later in the year.

A review of our booklet *Hepatitis C: what you need to know* is due to begin later this year.

Interferon

is provided through the Pharmaceutical Benefits Scheme (PBS) Section 100 Highly Specialised Drugs Program. To access the drug through this program, people must have:

- Chronic hepatitis proven by liver biopsy (except patients with blood clotting problems).
- A repeatedly positive antibody test.
- Liver function tests (with elevated ALT readings) three times over a six month period.
- Absence of cirrhosis or other liver disease.
- Absence of HIV infection.
- For women - not currently breast feeding nor any chance of pregnancy while under treatment.
- No history of significant psychiatric illness.
- Must be able to attend regularly for treatment & follow-up.
- Alcohol use of no more than seven standard drinks a week.
- No history of injecting drug use in the previous 12 months.

The course of treatment involves giving yourself an injection three times a week for up to twelve months.

The course of treatment must be continuous and excludes re-treatment of non-responders or people who relapsed. Consequently, people eligible for the 12 months course will be new patients. Treatment subsidy is also extended to patients who after the completion of 6 months therapy, choose to continue a further 6 months at their own expense. If their treatment has been continuous, the Commonwealth will subsidise the remainder of the second 6 month period.

If your ALT readings don't come down after three months, the treatment ceases to become available under the PBS. To continue at your own expense for the remaining nine months, the interferon would cost about $4,500.

Treatment centres

Interferon is classified as a potentially hazardous drug with possible serious side effects. Accordingly, this treatment is monitored closely.

Treatment centres ideally should have certain minimum facilities before they treat with interferon, including:

- A nurse educator / counsellor for patients.
- 24-hour access to medical advice for patients.
- An established outpatient liver clinic.
- Facilities to perform safe liver biopsy.

Treatment centres for hepatitis C exist across NSW (see below). You should make sure your centre has the minimum facilities listed above.

If you're eligible and have decided on interferon treatment, you'll then need to go to a treatment centre where you will again be briefed on the treatment and its side effects.

After clinical assessment which may take a couple of weeks, you will be given take home supplies of the drug.

You'll have to return for regular monitoring and further supplies. After treatment, your condition will be further monitored to determine how successful it was.

Current treatment centres include:

Bankstown Hospital
Bathurst Base Hospital
Bega District Hospital
Blacktown Hospital
Campbelltown Hospital
Concord Repat. Hospital
Corrections Health Service (Long Bay)
Dubbo Base Hospital
Illawarra Area Hospital
John Hunter Hospital (Newcastle)
Lismore Base Hospital
Liverpool Hospital
Mt Druitt Hospital
Nepean Hospital
Orange Base Hospital
Prince of Wales Hospital
Royal North Shore Hospital
Royal Prince Alfred Hospital
St George Hospital
St Vincent's Hospital
Sutherland Hospital
Wagga Wagga Base Hospital
Westmead Hospital

Side effects

Interferon makes most people feel ill and side effects can be serious. If you are thinking about this treatment, seek information about side effects from doctors who are up to date on hepatitis C and read the Council booklet, *Hepatitis C - what you need to know.*

Benefits

With twelve months of interferon treatment, it is believed that up to one in three people achieve what is called a 'long-term remission'. This means that the virus seems to be cleared from the person's blood and their liver function returns to normal. Symptoms related to the hepatitis C disappear as well.

[This information is routinely validated by the Commonwealth Department of Health & Family Services, Pharmaceutical Benefits Branch]

Natural therapies

have been used to treat hepatitis C and its possible symptoms but, to date, there've been few research trials in Australia to check their effectiveness.

Certainly though, many people report positive benefits.

Natural therapists using acupuncture, homeopathy and/or herbs aim to improve the overall health of their patients.

Good results have been reported by some people using natural therapies but others have found no observable benefits - and, as with any treatment, it's important to remember that wrongly prescribed medicines can be harmful.

Some people choose natural therapies as a first or a last resort. Others may not use them at all. Some may use them in conjunction with pharmaceutical drug treatments. Whichever way you choose, you should be fully informed. Ask searching questions of whichever practitioner you go to:

- Is the treatment dangerous if you get the prescription wrong?
- How have natural therapies helped people with hepatitis C?
- What are the side effects?
- Is the practitioner a member of a recognised natural therapy organisation?
- How much experience have they had of working with people with hepatitis C?
- How have they measured the health outcomes of their therapy?
- How do they aim to help *you*?

Remember, you have the right to ask any question of any health practitioner and expect a satisfactory answer. If you're not satisfied, shop around until you feel comfortable with your practitioner.

Costs

You cannot claim a rebate from Medicare when you attend a natural therapist. Some private health insurance schemes cover some natural therapies. It pays to ask your natural therapist about money before you visit them. Many will come to arrangements about payment - perhaps a discounted fee?

Choosing a practitioner

If you decide to use natural therapies, it's vital that you see a practitioner who is properly qualified, knowledgeable and well experienced in working with people who have hepatitis C.

It's also advisable to continue seeing your regular doctor and/or specialist. Talk to them and your natural therapist about the treatment options that you are considering and continue to have your liver function tests done.

It's best if your doctor, specialist and natural therapist are able to consult directly with one another. If a natural therapist suggests that you stop seeing your medical specialist or doctor, or stop a course of pharmaceutical medicine, *consider changing your natural therapist.*

Healthy herbs?

The use of herbal medicines to treat a wide range of conditions is being promoted world-wide by the World Health Organisation.

In regard to hepatitis, around 20 years of clinical research in Europe has already been completed on the herb *milk thistle*, which some people are using as a liver tonic here in Australia. In Germany, a standardised extract has been approved for treatment of various liver disorders including cirrhosis. There are no known adverse side-effects associated with short- or long-term use of this herb.

A recent Australian trial of one particular Chinese herbal preparation has shown positive benefits and few side effects (see edition 15.)

Want more information?

Contact any of the following organisations:

Australian Acupuncture Association	1800 025 334
Australian Homeopathic Association	02 9879 0049
Australian Natural Therapists Association	1800 817 577
Australian Traditional Medicine Society	02 9809 6800
Association of Remedial Masseurs	02 9807 4769
Homeopathic Association of NSW	02 9247 8500
National Herbalists Association of Australia	02 9211 6437
Register of Traditional Chinese Medicine	02 9660 7708
Australian College of Acupuncturists	02 4677 2358
NSW Association of Chinese Medicine	02 9212 2498
Australian Traditional Chinese Medicine Assoc.	02 9699 1090

NSW Hep C Telephone Info and Support Service

For confidential and anonymous information and emotional support you can phone the NSW Hepatitis C Telephone Information and Support Line.

9332 1599 (Sydney callers)
1800 803 990 (NSW callers)

The service gives you the opportunity to chat with trained phone workers and discuss those issues important to you. It also provides referral to local healthcare and support services.

Sexual health clinics

Although hepatitis C is not classified as a sexually transmitted disease, staff at these clinics can offer a range of services including pre- and post-test counselling, antibody blood tests, general counselling and primary healthcare (the type of service that GPs provide).

They are listed in your local phone book under 'sexual health clinics'. If you are concerned about confidentiality, these clinics do not need your surname and keep all medical records strictly private.

Community centres

Community Health and Neighbourhood Centres exist in most towns and suburbs. They provide different services, including counselling, crisis support and information on local health and welfare agencies. Some Neighbourhood Centres run a range of support and discussion groups and activities that may range from archery to yoga.

Community Health Centres can be found by looking in your White Pages under 'Community Health Centres'. Neighbourhood Centres can be found by phoning your Local Council.

Local support services

There are few hepatitis C specific support services. This isn't because of lack of need but because there have been inadequate resources to develop them, or integrate other appropriate services. So where does this leave you?

For particular assistance, whether it's help with the kids, housing, finances or home shopping, look in the White Pages telephone book. In the front, you'll find a whole range of services that are mostly aimed at the general community.

Following is a list of Infectious Disease Coordinators who work within local Area Health Services and can possibly refer you to local services:

Mid Nth Coast	Robert Baldwin	02 6583 0750
Western NSW	Chris Bourne	02 6885 8947
Hunter	Marilyn Bliss	02 4924 6477
Mid West NSW	Jeanine Buzy	02 6332 8576
SE Sydney	Colin Clews	9382 3694
South West NSW	Dalton Dupuy	02 6058 1700
Nthn Rivers	Wendi Evans	02 6620 7505
New England	Karin Ficher	02 6766 2288
Sth Wst Sydney	Ken Wong	9827 8033
Central Coast	Karen Nairn	02 4320 3399
Illawarra	Brian O'Neill	02 4228 8211
Wentworth area	Elizabeth O'Neill	02 4724 3877
Western Sydney	Chris O'Reilly	9843 3118
Central Sydney	Peter Todaro	9515 9600
Nthn Sydney	Anthony Schembri	9926 8237
Far West NSW	Darriea Turley	02 8088 5800
Southern NSW	Greg Usher	02 4827 3148

One-to-one counselling

Some people with hepatitis C may want to talk to a specialist counsellor who can provide special support or therapy when they have specific problems they're having difficulty dealing with.

Some situations where this may be useful include where someone has excessive anxiety about the outcome of their hepatitis C, or if they have a particular problem that impacts on their hepatitis C infection.

To find out more, speak to your GP, or contact your local sexual health clinic, Community Health and Neighbourhood Centres, or the NSW Hepatitis C Telephone Information & Support Service.

Also contact TRAIDS, the Transfusion Related AIDS & Infectious Diseases Service. Originally set up to provide counselling and support to people who contracted HIV through contaminated blood products, TRAIDS now also provides services to any people with HCV.

Family counselling

If hepatitis C is impacting on your family relationships, it may be wise to seek family or relationship counselling.

To find out more, speak to your GP; look in the Yellow Pages under 'counselling'; contact Family Planning or your local Community Health or Neighbourhood Centre; or phone the NSW Hepatitis C Telephone Information & Support Service (see top left of page).

←

regular feature - available information

Except for videos, these resources are available free of charge.

Videos are borrowed for two weeks at a time and will cost you the return postage. Phone or write and tell us what you'd like - but please do not send any payment for videos - just pay for the return postage when you post them back to us.

Description	Description
Newsletters 1-8 back issue pack - various topics / historical interest	***Hepatitis C - a brief introduction*** - (brochure @ $5 per 100)
Ed 9 - Chiron's patent / living with grief	***Hepatitis C - what you need to know*** - (booklet @ $1 each)
Ed 10 - natural therapies	***Video 1 - interferon / HCV & women*** - (you pay return postage)
Ed 11 - genome subtypes / life insurance / Terrigal symposium	***Video 2 - homeopathy / herbalism*** - (you pay return postage)
Ed 12 - drug law reform / HCV fatigue / women & HCV	***Video 4 - hepatitis C / the liver*** - (you pay return postage)
Ed 13 - HCV & prisons / 94-95 annual report	***Research Pack 1*** - epidemiology / prevention / serology / diagnosis
Ed 14 - discrimination / drug law reform / DSS / clinical trials	***Research Pack 2*** - overview / National Action Plan
Ed 15 - partying safe / informed consent / stress / Nat AIDS strategy	***Research Pack 3*** - 1994 NHMRC Hepatitis C Report
Ed 16 - diet & nutrition / DSP changes / IDU & hep C Councils	***Research Pack 4*** - surveillance / post-transfusion HCV / herbalism
Ed 17 - study grants / HCV & relationships / Australasian conference	***Research Pack 5*** - AHMAC / NSW Taskforce Report
Ed 18 - Parliamentary Inquiry / HCV & IDU / safe disposal	***Research Pack 6*** - prisons / treatment / IDU / PCR
Ed 19 - notifications / diagnosis / understanding research	

We have an abridged version of our booklet on our website. Look for it at .. **http://www.span.com.au/hepatitis_c/info.html**

membership fees

Unless you're paid up till 1999, your annual membership fees will become due on 1 March. Please feel free to send in your fees earlier as this greatly assists Prue, our hardworking admin staffer.

We are not a well funded organisation. If you are working full-time, your fees would be $25; if you work part-time or are on a pension or other Govt benefit, your fees would be $10. If you don't have any real form of income (if you are in prison, etc.) your fees would be $0.

NEW MAILOUT DATES

We're planning to alter our magazine mailout dates so that key production dates don't clash with school holidays. We'd love to coincide our holidays with those of our (school aged) children. New mailout dates will be 1st week of March, June, September & December.

Our apologies for the subsequent four week delay in distribution of our next edition due in June.

All following editions will arrive every three months as usual.

Hep C Classifieds Hep C Classifieds

Share accommodation

Share with one male in 2 bedroom unit in Lakemba. Very close to train station and shops.

$80 per week, all inclusive. Smoker OK but no alcohol or drugs.

Ring any day after 12 noon.

ph: 9759 8979

Footy social club

Is anyone interested in getting together to see Sydney Friday night games in this coming League season?

Anyone is welcome - doctors too.

If you're interested, call me on 9332 4132

- Olly

Who said nothing is for free?

Classifieds cost absolutely zero. If you have something to sell, flats to rent, jobs to advertise, work wanted, etc., just give Paul a call on 9332 1853.

(Following this edition, No 20, editions will generally be posted out each 1st week of June, Sept., Dec. & Mar)

Hepatitis C Council of NSW

MEMBERSHIP FORM

Please complete as much of this form as possible.
Our policy is to respect your privacy. All details on this form are treated in the strictest confidence and all communication is carried out discreetly.

Please return this form with your cheque, money order or credit card details to:

Hepatitis C Council of NSW
PO Box 432 DARLINGHURST NSW 2010

Make cheques out to *Hepatitis C Council of NSW.*

1. Please complete either a, b or c.

a. For people affected by hep C, or other interested people.

Name			
Postal address			
Suburb / Town			
State		Postcode	
hm phone		Wk phone	

b. For individual healthcare or welfare professionals.

Name			
Occupation			
Postal address			
Wk phone		Wk fax	
Mobile phone		Email	

c. For agencies, companies and organisations.

Organisational name			
Contact person			
Position			
Postal address			
Wk phone		Wk fax	
Mobile phone		Email	

2. If you can help with any of the activities listed below, please tick the following boxes.

Admin and office work?	
Other?	

3. Is this a renewal, or are you a new member?

Renewal		New member	

4. Please circle one membership fee box.

Membership fees are due annually on 1 March. We welcome a full year's payment but would not want financial hardship to prevent you from becoming a Council member. If this is the case, please circle the concession or zero fee box.

Waged	$25	Professional healthcare worker	$40
Concession	$10	Community-based organisation	$50
Zero Fee	$0	Public/Private sector organisation	$70

5. Separate donations are gratefully accepted by the Council.

If you make a separate donation, please record the amount here. $

6. If paying by credit card, please complete this section.

Card type (please circle): Mastercard | Visa | Bankcard

Card number

Expiry date: month ____ year 19____

Cardholder's signature

Cardholder's full name

7. Do you require us to send your receipt? Membership fees are not normally tax deductible. To reduce postage costs, receipts are not normally sent. If you want us to send your receipt, please tick here. →

8. Declaration. I accept the objects and rules of the Hepatitis C Council of NSW and apply for membership of the Council.

Signed Dated

This section is	Date received	$ received	Receipt no.	Date entered	Member no.	Info pack
for office use only						
staff initials						