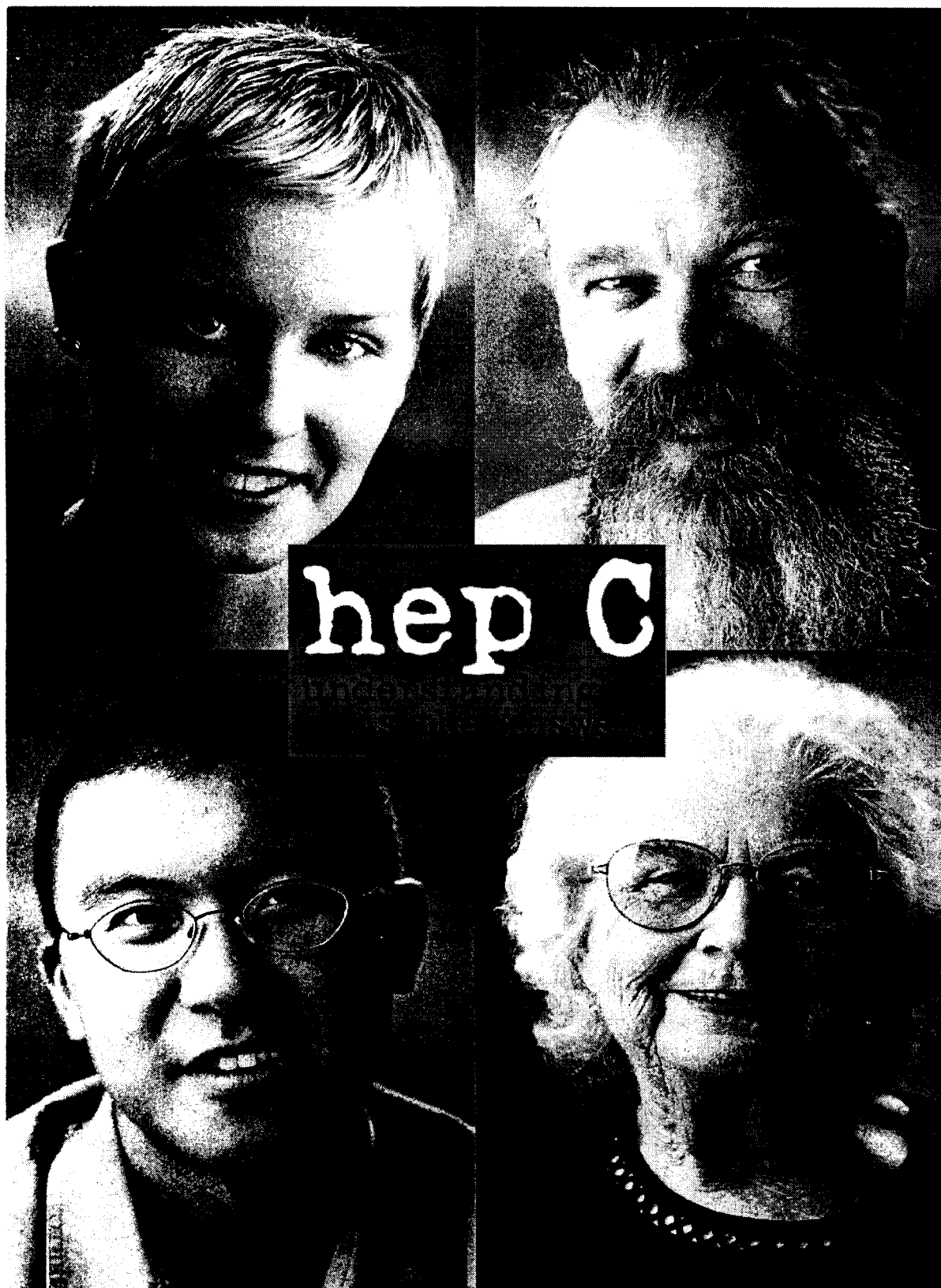


The Hep C Review

Winter Edition June 2000

Edition 29



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Just say no to America

Australia is taking the correct approach to tackling the drug problem, writes Dr Ernest Drucker.

As an American public health professional who has worked for more than 30 years in the treatment of drug addiction and, more recently, in research on AIDS prevention, I have followed the twists and turns of your [Australian] national debate on the establishment of safe injecting rooms and heroin trials with more than casual interest.

In my own country, command centre of the global war on drugs, such a debate would be impossible and the actual implementation of such programs still unthinkable.

The US Government effectively dominates local and State drug policies and has banned Federal funding for all harm minimisation activities as "sending the wrong message", claiming they are thin covers for drug legalisation. This, even as 10,000 to 15,000 Americans die from drug overdoses each year and more than 20,000 new HIV infections occur among the nation's one million to two million drug injectors (about 200,000 of whom already carry the AIDS virus).

Some localities continue to prosecute their own citizen activists who, defying the laws, continue to distribute clean injecting equipment. Eleven States still ban methadone treatment altogether - despite the fact that research has clearly demonstrated that both approaches slow the spread of AIDS.

What we do instead, and with a vengeance, is incarcerate drug users. And we do so at a fearsome rate - having last week placed the two millionth American behind bars, an American who most probably is a drug user. Today, the US imprisonment rate is about four times that of Australia and has increased 100 per cent in the past decade alone. Most of this increase is associated with harsh mandatory sentences for drug use.

But the US is not content to impose this insanely self-destructive approach upon its own citizens alone. We insist that other nations do likewise and tow our line of "zero tolerance". The US has done everything in its power to influence the Commonwealth to desist from the very innovations that have already saved so many Australian lives (such as needle exchange and the involvement of drug user organisations) and objects strenuously to others that can save more lives if implemented - ie, the heroin trial, and most recently, the safe injecting rooms.

I am once again filled with admiration for Australia's compassionate pragmatism, in drug matters .. and its courage to do the right thing - even in the face of strong outside pressures to abstain from the sort of harm minimisation strategies that have already saved thousands of Australian lives.

But great powers like the US have other ways to make their feelings known. Last week, the United Nation's International Narcotics Control Board (INCB) which the US also dominates, issued a press release in which it accused Australia of violating international narcotic treaties if it went ahead with plans for safe injecting rooms.

The INCB claimed that such programs are not in line with international conventions and that the explicit or tacit approval of so-called drug injection rooms - or shooting galleries - are seen as a step in the direction of "drug legalisation". Sound familiar?

Most experts on international law who understand the actual power and mandate of the INCB dismissed its assertions as a hollow threat. But the INCB will visit Australia in April - just as the first injecting rooms are getting set to open in Sydney. No doubt it will repeat its view that these facilities not only promote tolerance towards illegal drug use and trafficking but also run counter to the provisions of the international drug control treaties. The INCB will assert that any national, State or local authority that permits the establishment and operation of such drug injection rooms also facilitates illicit drug trafficking.

This refrain echoes similar statements made a few years ago about the meticulously planned heroin trial that was then set to begin in the ACT. In that case a series of calls and visits from Washington and Vienna (home of the INCB) and open threats against your Tasmanian opium industry carried the day and the heroin trial was stopped by the Federal Government - despite its prior approval by your State health ministers. Such heroin programs have since been successfully implemented in Switzerland and the Netherlands. They will soon begin in Germany and are planned for Spain and Italy.

And, of course, this approach echoes US policy at its most retrograde, characterising even sound scientific trials of new approaches and other public health measures of proven effectiveness as devious routes towards drug legalisation.

Why would a country, normally so generous of spirit and so famously open to innovation, adopt a posture so lethal to its own citizens? And more to the point here in Australia today, why would the US complain so bitterly about another distant country's choice of a more pragmatic and humane path? Why would we attempt to impose our own clearly faded approach on others?

A partial answer can be drawn from the work of the Australian critic Robert Hughes, who has lived in America for more than 20 years. Hughes likes America. He readily speaks of his "visceral attachment" to it ("next to Australia, America is a place I know and love best") and has become unusually perceptive about its people and culture.

In a series of lectures given at the New York Public Library in 1992, Hughes spoke of the "fraying of America" by the success of *populist demagoguery* [playing on the passions or prejudices of the population], and an America with "a distrust of formal politics; sceptical of authority and prey to superstition; its language corroded by fake pity and euphemism".

How else can we comprehend sentencing tens of thousands to long prison sentence because they have a problem with drugs? He speaks of a "culture of complaint" that is overtaking American thought and threatens to "unravel that sense of collectivity and mutual respect". A culture that has "broken the traditional American genius for consensus, for getting along by making up practical compromise to meet real social needs".

Thus, while many American politicians tell us in private that the war on drugs is a fiasco, there is no public debate about any of it in any actual political forum - the sceptics silenced by well-grounded fears of political retribution, fears of being called "soft on drugs" by demagogic opponents. The appalling casualty rate our citizens continue to pay for this mishandling of our own huge drug problem is the price we pay for this hypocritical lapse in moral judgement.

The stunning success of your approach to AIDS (Australia having averted an epidemic among its drug users) is one of the things that has drawn me back here - to learn from your fine public health professionals and emulate their programs wherever possible in the US. And while hepatitis and overdose remain massive problems here - as everywhere else in a world awash in illicit drugs - you have the foundations of intent and a willingness to examine outcomes that are the prerequisite to effective policies.

So now that the nation's first injecting room is soon to open in Kings Cross (with others to follow in Victoria and elsewhere), I am once again filled with admiration for Australia's compassionate pragmatism, in drug matters. And its courage to do the right thing - even in the face of strong outside pressures to abstain from the sort of harm minimisation strategies that have already saved thousands of Australian lives.

Good on you!

- Dr Ernest Drucker is Professor of Epidemiology and Social Medicine at New York's Montefiore Medical Centre / Albert Einstein College of Medicine.

Abridged with thanks from the *Sydney Morning Herald*, 6 March 2000.

←

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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. We are primarily funded by NSW Health.

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"McCombo" hype?

"A radical new treatment" announces a reporter on the ABC's *7.30 Report* (28 February). The reporter then reveals that the radical new treatment is combination therapy. Was this a genuine news story or yet another pseudo story initiated by drug company public relations hype?

Certainly, McCombo therapy has, so far, demonstrated an improved response rate when compared to interferon used on its own, however such TV news stories are an extremely effective way for those drug companies engaged in the manufacture of drugs with questionable efficacy to maximise making a heap of money in the window period before better treatments become available.

Personally, I prefer to wait until something better and in my view, safer, comes along.

Yours, John



Responding to "Pill Problems"

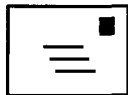
[In response to "*Pill problems*", a letter carried in Ed 28 page 6, concerning the Mirena birth control device - a small T-shaped IUD which after insertion, releases the hormone, levonorgestrel.]

Fiona, most women with hepatitis C would almost certainly be safe using the Mirena birth control device. Prescribing general practitioners should be recommending regular liver function tests to help monitor what is happening.

Yours sincerely

Robert G Batey

Gastroenterologist/Hepatologist



Informed decisions

My father suffers from hepatitis C and is currently waiting information as to the extent of damage to his liver. He is only 43 and when we were told that he had the virus it was mainly scary because we really didn't know anything about it. In fact I had not even heard of it.

I would like to thank you for your information which has clarified a number of questions in my mind which in turn I have been able to relay to my family.

Although we cannot help to cure my dad, now that he knows more about it he can make informed decisions on what treatments to take and what he should do about his diet - and finally I have an excuse to nag him to quit smoking!

Again, thank you for your good and worthy cause.

Regards

Corrina.

Corrina, also see our information about treatments (page 40) and liver biopsy (Ed 20, page 28). Ed



My treatment

I was on a six month course of interferon and ribavirin.

I have had my blood test for any signs of the virus and it has come back clear. That was three months after I finished the treatment. I have to have another in three month's time.

I'm writing to say thanks to you for the information you have sent. I've found it very informative.

I have also phoned the Helpline and it was very pleasant and understanding.

Thanks again and keep up the good work.

Name supplied



Share me around

It was very interesting to read "Share it around" (Edition 28, Page 5) and I have attempted to express my feelings about being refused the chance to become a body donor when I depart this planet.

Following an operation in 1979 I was given a blood transfusion. In the following years, apart from always feeling tired and lacking energy, my general health has been okay.

During 1992 I had a further operation and to avoid taking risks I decided to bank my own blood. However, imagine my surprise at being told I could not do this as I was hep C positive. This was traced back to the blood transfusion in 1979.

Further down the track, my wife and I decided to become body donors and leave our remains to the local University. This was okay for my wife but because I revealed my hep C I was not considered suitable as a donor.

I can understand the University having real concerns for their staff and students in handling HCV positive blood, etc. However I feel there could be a great deal to be learnt about the long term effects of hep C on the body and organs - in my case 20 years plus.

I wonder if anyone else has had a similar experience. I will be looking forward to reading any comments in future editions of *The Hep C Review*.

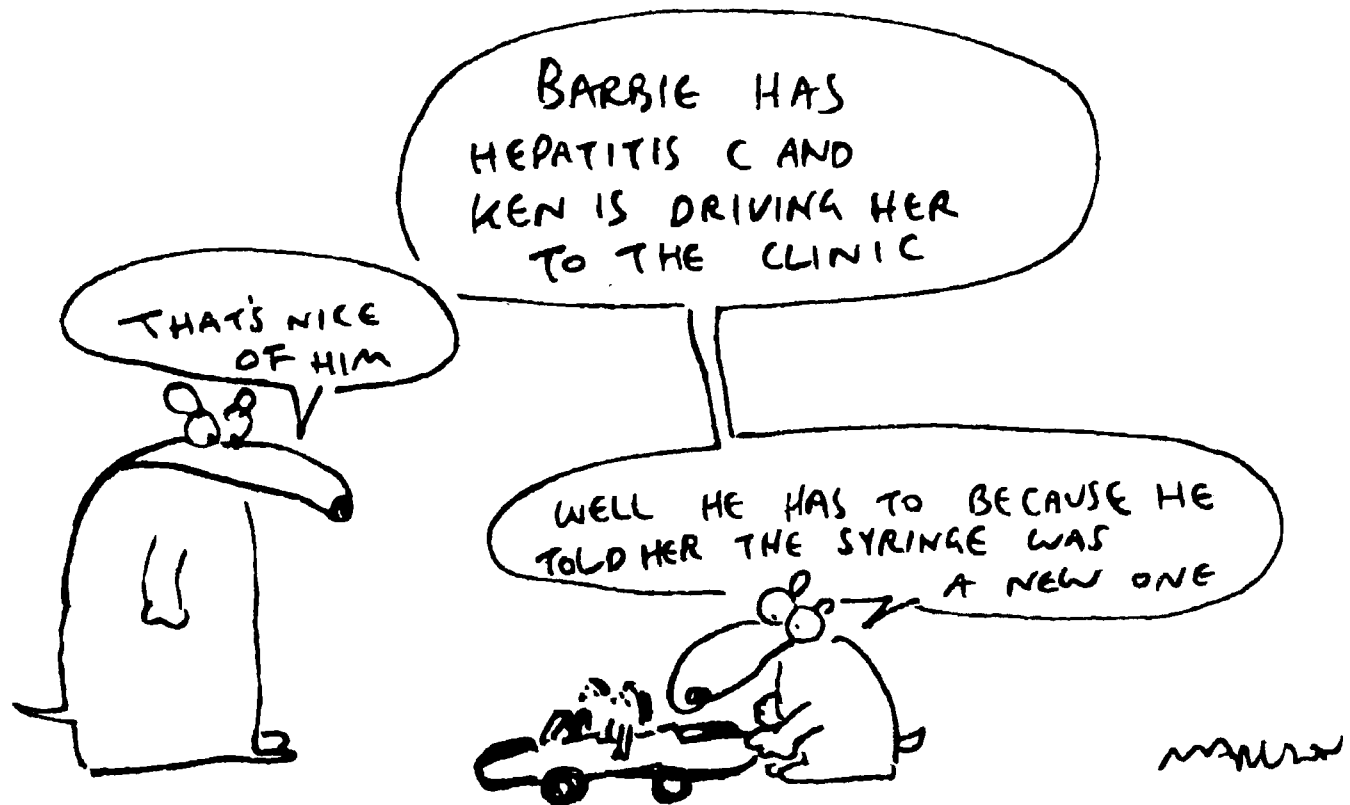
Don, Newcastle



Pearly whites?

Are your teeth falling out from dry mouth syndrome? One of those nasty hep C side effects. Apparently this mouth rinse is supposed to be used at bedtime and it kills off the harmful bacteria for the night - Chlorhexidine Rinse Compound 0.2%. It is the dry mouth that lets those tooth destroyers work.

Good Luck, Marjorie



Team finds cell gene that helps viruses multiply

Science Daily

Scientists have found a cellular gene that is commandeered by a virus to help it multiply. The finding, made by a team of scientists from the Howard Hughes Medical Institute at the University of Wisconsin-Madison's Institute for Molecular Virology (USA/Canada), is important because it gives critical insight into the relationship between virus and host cell. It could provide the basis for new genetic strategies to contain RNA virus infections such as those that cause hepatitis C and the common cold.

"This is the first genetic identification of an *intracellular* [inside a cell] host factor that contributes to the ability of the virus to copy its genes," says Paul Ahlquist, an investigator at the Howard Hughes Medical Institute. "Loss or mutation of this gene severely inhibits multiplication of the virus."

Identifying the contributions made by host cells to invading viruses is a critical frontier in virology. Until now, intracellular factors involved in RNA viral infection had not been conclusively identified, despite a number of biochemical and genetic clues. Previously for RNA viruses, the only host factors identified were cell *surface proteins* ["keyholes"] that help viruses enter the host cell.

The Wisconsin work was done in yeast - an organism whose entire *genome* [genetic structure] is known to science - but it has implications for understanding how the large family of RNA viruses works in humans, animals and plants. RNA viruses make up about a third of all known viruses and include hepatitis C, which infects hundreds of millions of people worldwide; polio, encephalitis and hemorrhagic fever.

A better understanding of how resource-poor RNA viruses use host cells to multiply is essential to developing strategies to ward off viral infections, says Ahlquist. The discovery of a gene that underpins a key step in the chain of viral infection provides important insight into the complicated interplay of virus and host cell.

It could one day lead to antiviral drugs effective against a broad spectrum of viruses. Moreover, it could negate the viral advantage of high genetic mutation rates, the ability of a virus to change in order to avoid host defences.

- Taken with thanks from the internet email list, HEPV-L

Viramune linked to liver damage

By Richard Woodman (Reuters Health)

An urgent safety restriction has been issued by the European Agency for the Evaluation of Medicinal Products (EMA) following reports of sometimes fatal *cutaneous* [skin] and *hepatic* [liver] reactions associated with the AIDS drug Viramune (nevirapine).

In a statement, EMA said, "most of the cases of hepatitis were reported to be within the first 8 weeks of treatment, some of them associated with hypersensitivity reactions such as fever, rash, *arthralgia* [joint pain], *myalgia* [muscle pain], *hypereosinophilia* [blood disorder] or acute *renal* [kidney] failure."

An EMA spokesman was not immediately available to say how many severe reactions and deaths had occurred but said that the dosing of nevirapine must be strictly followed.

Patients should also be intensively monitored during the first 8 weeks of treatment. In regard to hepatic reactions, close liver function monitoring must be performed especially during the first 8 weeks of therapy.

Nevirapine should be stopped and never re-administered in people with AST or ALT greater than 2x upper normal limit associated with hypersensitivity reactions or hepatitis, the statement said.

Available for use in Australia, Viramune is a non-nucleoside reverse transcriptase inhibitor, which is *indicated* [suggested for use] in people with HIV who have advanced or progressive immunodeficiency.

SOURCE: Journal of the American Medical Association HIV/AIDS News
<<http://www.ama-assn.org/special/hiv/newsline/reuters/04197989.htm>>

- Taken with thanks from the internet email list, HEPV-L

Up to 16 million a year get hepatitis B from dirty syringes

The World Health Organization (WHO) reported recently that between 8 million and 16 million people are infected with hepatitis B through dirty or reused needles every year.

In a statement, the WHO noted, "Although most medical injections given in the world follow safe clinical practices, poor injection practices [often carried out by non-medically trained persons] continue to transmit viral hepatitis and other infections on a large scale in many countries."

- Taken with thanks from the internet email list, HEPV-L

Clue helps predict people who clear HCV

Researchers studying hepatitis C have found a clue that may help them predict which people will initially recover and which will develop the chronic form of the condition.

"There is something at play in earliest stages of infection where you can really see the destiny of the infections," said Dr. Patrizia Farci of the University of Caligari in Italy.

The finding, reported in the journal *Science* (14 April 2000; 288: 339-344), opens new avenues to improving the understanding of the body's immune response to the hepatitis infection, she said.

"In people who initially recover from hepatitis C, you see a dramatic decrease in genetic diversity, whereas in those who progress to chronicity you see that there was a dramatic increase in the *genetic diversity* [quasispecies] of the virus," she said.

This became evident in the first 10 to 12 weeks after infection, she said, theorising that those who are able to recover from the infection have more effective immune responses which gradually eliminate each form of the virus until it is cleared. In other people, the virus can evolve into many different *quasispecies* [myriad forms of the one viral subtype, all having minute differences], making it harder for the body to battle, and leading to a chronic infection or acute form of the disease.

The finding will help physicians better predict the outcome for people and may lead to new research into the immune system and ways to help people fight the disease, Farci said.

- Taken with thanks from the internet email list, HEPV-L

Should treatment be extended to more people?

St Louis (USA) University School of Medicine researchers are studying people with hepatitis C and normal liver enzymes (alanine aminotransferase, or ALT) to determine if they have the same treatment response as people with elevated liver enzymes.

"Current medical recommendations exclude those people with normal or low ALT levels from treatment with the leading drug combination therapy, but we believe early drug intervention may protect these people from more severe complications of the disease," said Bruce R. Bacon, M.D., Professor of Internal Medicine, Division of Gastroenterology and Hepatology, Saint Louis University School of Medicine.

"This study will determine if it makes sense to help people before their condition worsens by reducing or eliminating the hepatitis C virus in its early stages." According to Dr. Bacon, elevated enzyme levels should not be the sole determinant of virus activity or of significant liver disease.

Approximately 2,500 people with normal liver enzyme levels will be treated for up to 12 months with Rebetron combination therapy.

"We hope the results of this study will be a call to action for medical professionals to reduce the inadequacies in current treatment guidelines for hepatitis C patients," said Bacon. "Physicians should consider further testing and potential administration of combination therapy to patients with normal ALT."

Saint Louis University is a co-educational private university, sponsored and assisted by the Society of Jesus (Jesuits), located in Saint Louis, Missouri. Established in 1836, Saint Louis University School of Medicine is a pioneer in organ transplantation, chronic disease prevention, cardiovascular disease, neurosciences, vaccine research and geriatrics, among others.

- Taken with thanks from the internet email list, HEPV-L

ZZ Top scraps European tour

Blues rock band, ZZ Top, has canceled its upcoming European tour after bassist Dusty Hill was diagnosed with the hepatitis C virus.

"I want to extend my deepest apologies to the ZZ Top fans we may have disappointed," Hill says in a statement. "The prognosis is very good and with the help of physicians and family, I hope to see you sooner rather than later."

The group says that thanks to early detection and with new and advanced drugs and extended rest, "Dusty can look forward to a hopeful recovery."

Some 35 concerts in 17 countries were canceled and would be reinstated later, the band says.

ZZ Top had completed some 100 dates on its 30th anniversary tour in North America, Australia, and New Zealand before Hill complained of fatigue and consulted a doctor. The group's latest album, XXX, has sold more than 100,000 copies in the United States since its release last September.

- Source: www.hepcbc.org & Reuters.
Taken with thanks from the internet email list, HEPV-L

Hepatitis C linked to type II diabetes

By Emma Patten

Type II diabetes (diabetes mellitus) may be associated with hepatitis C virus infection, according to researchers at the 10th International Symposium on Viral Hepatitis and Liver Disease (ISVHDL).

Shruti Mehta and colleagues from the Johns Hopkins University examined data from the third National Health and Nutrition Examination Survey (NHANES III), conducted between 1988-1994 in the US. Of the 9841 subjects over the age of 20 who were assessed for diabetes and HCV infection, 1242 (8.4 percent) had diabetes (type 1 and type 2) and 230 (2.1 percent) were anti-HCV positive.

After adjusting the figures to account for factors such as age, race, and socioeconomic status, the researchers found that people with HCV were four times more likely to have type 2 diabetes than people without HCV.

They found no *association* [linkage], however, between HCV infection and type 1 diabetes. Similarly, they found no association between hepatitis B virus (HBV) infection and diabetes types 1 or 2.

Suggesting a cause for the association, Mehta told Doctor's Guide that "it might be a combination of factors that produce this association. Hepatitis C virus has been shown to replicate outside the liver and in the pancreas so it could be that HCV may be causing some concomitant beta cell dysfunction."

Mehta could not confirm whether the fact that diabetics have to inject themselves could cause HCV transmission or if HCV transmission caused beta cell dysfunction and, consequently, diabetes. "We're not sure what the mechanisms are or which condition causes which," she said.

"Providers should consider screening persons with one condition for the other since the adverse outcomes of each can be medically prevented," she added.

- Doctor's Guide to Medical News <<http://www.pslgroup.com/dg/lccfe6.htm>>

Taken with thanks from the internet email list, HEPV-L

US grants orphan drug status to Zadaxin

The United States Food and Drug Administration (FDA) has granted Orphan Drug Status to Zadaxin (thymalfasin) for the treatment of *hepatocellular carcinoma* [liver cancer], the most common form of liver cancer worldwide. Orphan Drug Status provides for US marketing exclusivity for seven years upon marketing approval.

Worldwide, there are approximately 1,000,000 new cases of hepatocellular carcinoma each year and there is a strong association between hepatocellular carcinoma and chronic hepatitis B and C.

Many patients with cancer and chronic infectious diseases have an impaired immune system. Zadaxin significantly enhances the immune system's ability to recognize and destroy cancerous and infected cells. Zadaxin immunotherapy is in late-stage development for cancer and viral hepatitis worldwide.

- SOURCE: Doctor's Guide to Medical News <<http://www.pslgroup.com/dg/192dee.htm>>

Taken with thanks from the internet email list, HEPV-L

Improved access to PCR testing

The Federal Minister for Health and Aged Care, Dr Michael Wooldridge, has endorsed government funding of viral load and genotype testing for certain use within hepatitis C treatment.

People with hepatitis C are currently able to access government funded PCR detection tests - to help confirm their HCV status in cases when antibody testing is inconclusive. The new access arrangements will additionally allow for:

- One PCR genotype test - when initially considering treatment options.
- One PCR viral load test prior to therapy - should someone decide to proceed with interferon or combination therapy.
- Four PCR viral detection tests prior to and over a 12 month treatment/ follow up period - to help monitor treatment response.

(Also see page 19 for more information.)

Improved blood screening tests

As part of a national initiative, the NSW Minister for Health, Mr Craig Knowles, recently announced \$2.6 million in funding for improved screening of blood donations.

The introduction of Nucleic Acid Amplification Testing (often known as PCR testing) will allow Blood Banks to detect, at an earlier stage, a range of blood borne contaminants including hepatitis C virus and HIV.

"This new initiative will ensure that the Australian blood banking system continues to operate at world class standards," Mr Knowles said.

Living with hep C study

Max Hopwood and Erica Southgate of the National Centre in HIV Social Research, University of NSW, Sydney, are beginning a study which aims to gain an understanding of people's experience of living with hepatitis C.

While the study is in its early stages, a number of areas for investigation are being identified. These include the psycho-social effects of a positive HCV diagnosis, interactions of clients with health professionals, sources and meanings of support, and quality of life issues.

It is envisaged that a combination of qualitative and quantitative methods for data collection will be employed. In the near future, Max Hopwood will be conducting a consultation process so that the study can be informed by the insights of people living with HCV, health professionals and other service providers.

- Further information is available from Max on (02) 9385-6436 (m.hopwood@unsw.edu.au).

Hepatitis & health survey

The National Centre in HIV Social Research at the University of New South Wales, in collaboration with the Australian Research Centre in Sex, Health and Society at La Trobe University, is conducting a Hepatitis and Health Survey among high school students in New South Wales.

Seventy-five schools from across the State were selected at random. Within each school, one Year 9 and one Year 11 class, also selected randomly, will complete the survey. As at the beginning of May 2000, 35 schools had already agreed to participate and questionnaire completion was underway in these schools.

The Survey follows the recent NSW Hepatitis C public awareness campaign and will provide up-to-date information on high school student's information, understandings and risk practices in relation to hepatitis.

- Further information available from Dr Paul Van de Ven on (02) 9385-6445, (p.vandeven@unsw.edu.au).

New injecting resources

Complementing the recent NSW public awareness campaign, two new HCV-related information resources have been developed by the NSW Users & AIDS Association (NUAA).

The first is a 16 page HCV focused supplement to be circulated within NUAA's upcoming edition of *User's News*. With a circulation of 30,000, this supplement will be able to provide injecting communities with up-to-date information.

The second resource consists of two pocket-sized booklets: one dealing with preventing transmission through "blood awareness", the second describing and comparing the various main forms of viral hepatitis - HCV, HAV, HBV.

- Further information available from Gideon, on 02 9369 3455.

Within Edition 28, we said that we would provide an update on the options open to Australian Defence Force personnel who test HCV positive (see news item, "Ban on positive soldier", page 7)

We are liaising with the Australian Defence Force medical services unit but have unfortunately not yet been able to finalise the article.

We will print it as soon as possible.

Ed.

Streetwise hits the streets

The Streetwise comic, *Hit me with your best Shot*, aimed at providing blood borne virus prevention messages to young people at risk from HCV infection is now ready for distribution.

An initiative of Western Sydney Area Health Service, the comic has been produced by NSW Health for statewide distribution through Needle & Syringe Programs.

NSW Hepatitis C workforce development project

The NSW Health AIDS/Infectious Diseases Unit has recently provided funds to set up a new project that will build on the outcomes of the NSW HCV Health Care Worker Education Strategy Project (PHOFA funded), hosted by the Hepatitis C Council during 1999. The new project will target networks of health services (Area Health Services and sectors within them) to help health care providers better meet the needs of their clients.

The project will support the development of locally appropriate HCV-related strategies, programs and services within a context of limited resources. It will offer a series of practical tools to lead to the development of individual, workplace and service network action plans that are specific, client-driven and achievable.

This statewide project will operate from within NSW Health Study Grants Program and will have strong links with key stakeholders which include the Hepatitis C Council of NSW.

Edition 28 corrections

Within "Identification and management of dry mouth in hepatitis C" (Ed28, page 18), our reference to pilocarpine solution should have read: 0.5mg/ml, 5ml qid.

Additionally, our reference to the medical journal *Australian Family Practitioner* (page 10) should have read *Australian Family Physician*.

Our apologies for any resulting confusion.

Gender difference and hepatitis C

By Paul Harvey

Like most viruses, the hepatitis C virus fundamentally does not discriminate. Although there are slight nuances and trends, it infects women just as easily as men - and it will generally have a similar effect on people's health, be they male or female.

Prevalence & incidence trends

Up to the end of 1997, over 110,000 notifications had been reported in Australia. A gender trend has emerged with close to twice as many males as females returning positive HCV antibody tests.

In contrast, information from an ongoing study involving around 20 Australian needle and syringe programs suggests a higher prevalence of HCV among women (MacDonald M, et al. MJA 17 Jan 2000;172:57-61). This trend is most pronounced among young people (15-24 years).

A relatively high hepatitis C prevalence among young women who inject drugs may be related to sharing with older male partners - who have been injecting longer.

However, the number of men responding to the survey was more than double that of women suggesting more men inject drugs than women which may explain the gender bias of overall notifications (top).

Chronicity

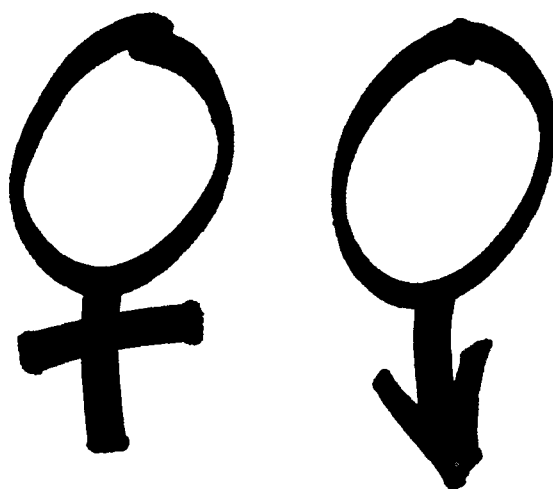
A 1996 study involving 96 persons (Love A, et al. American Journal of Epidemiology, 143, 6:631-636) suggested that significantly fewer females than males had detectable HCV viral RNA in their blood [were PCR positive]. The researchers believed that women eliminate the hepatitis C virus more effectively than men.

Larger studies, however, do not support this belief. A recent study by Spencer J, et al., involving 789 persons (as yet, unpublished) found that factors such as gender, age, ethnicity or drug taking habits were not important predictors of infectiousness. Further studies may shed more light on this area.

Illness outcome

Some recent studies have suggested a slower progression of hepatitis C liver damage in women, (see recent study by Roudot-Thoraval F, et al. *Hepatology*, 26:485-490). Supporting this suggestion is Australian research showing that liver cancer is generally more common in men than in women whether due to hepatitis C or other causes (Khan M, et al. *Hepatology*, 31:513-520).

The reasons why hepatitis C (and many other diseases) may be different in women than in men are unclear, although research is starting to unravel an interesting sex difference between the way in which males and females develop scarring of the liver.



Hormonal effects

Although both men and women use products such as growth hormones, this issue primarily relates to women, specifically in regard to menstrual cycle and menopause.

In most cases, women's menstrual cycles are not affected by hepatitis C virus. Should irregularities occur, general practitioners or women's health practitioners can provide a health checkup to clarify if other health problems are involved.

It is believed that women with quite serious liver damage may experience intolerance to the oestrogen based contraceptive pill or hormone replacement therapy. General practitioners,

endocrinologists [hormone specialists] or women's health practitioners should be able to provide advice in this area.

Treatment response

People are taking up antiviral treatment at a similar gender ratio to HCV notifications - roughly 2 men for every 1 woman (National Hepatitis C Database Project, 1999).

It is generally acknowledged that complex interplays between genotype, viral load, age at acquisition of HCV, alcohol use and present level of *fibrosis* [liver inflammation] play the primary roles in determining antiviral treatment outcome (Sievert W, Korevaar D. Aust Fam Physician 1999;28:SI40-45).

One small study has suggested, though, that in addition to the above, more commonly mentioned factors, male gender, racial background and post-menopausal state for women (oestrogen &/or progesterone) are associated with a lower probability of responding to interferon-based therapy (Colantoni A, et al. Antiviral Therapy 1999; 4 Supplement 4, 38). Future studies may confirm what effect gender and hormone levels have on determining treatment outcome.

- Paul Harvey is Special Projects Officer at the Hepatitis C Council of NSW.

Thanks to Dr Greg Dore, National Centre in HIV Epidemiology and Clinical Research, for editorial assistance.

Responding to "Iron Overload"

In response to Jean's personal story, "Overloaded with Iron", Ed 28, page 19.

It is interesting to read your letter and to realise that you have been diagnosed with haemochromatosis. The frequency with which you have had venesections would suggest that you have more than just the excessive iron found in the liver of some patients with liver disease - of any sort.

It is evident that all types of liver inflammation can occasionally signal to the bowel to absorb too much iron and in your case you have had quite a lot of blood taken off and you would appear to have the inherited form of iron storage disease, namely, genetic haemochromatosis.

It is true that iron plus hepatitis C, hepatitis C plus alcohol, iron plus alcohol combinations all cause more liver injury than any one of the insults on their own.

If you have haemochromatosis you are one of a very significant population of patients with this very common genetic disorder. I hope you have had the genetic test for haemochromatosis carried out so that other family members can be advised with testing as to whether they are at risk of this condition. About 1 in 300 in the general population do have iron overload.

Thank you for raising this matter for the readers of *The Hep C Review*.

Yours sincerely

Robert G Batey

Gastroenterologist/Hepatologist



Regarding Jean's story

In response to Jean's personal story, "Overloaded with Iron", Ed 28, page 19.

It sounds like Jean has two problems - hepatitis C and iron storage disorder, haemochromatosis. When people have more than one medical problem, it is a good idea for them to ask their doctor to write it down, so that they can investigate each individual aspect.

Haemochromatosis is a genetic disorder which is extremely common in people of northern European origin, but much less common in people whose forebears come from other parts of the world. Because so many early white Australians came from the British Isles, the frequency of the gene in Australians is common - about one person in 12 carries one copy of the haemochromatosis gene. Because this genetic disorder is what is called a recessive (only people with two abnormal genes have the disease) the actual disease manifestations occur in about one person in three hundred.

In previous times, haemochromatosis led to cirrhosis of the liver and diabetes, but now the disease is readily diagnosed by a gene test (on blood), as well as by iron studies from blood tests. Complications of the disease (cirrhosis, liver cancer) can be prevented if the iron is removed early, as appears to be happening in Jean's case with regular venesections.

After that the story gets more complex! It has been found that people with increased liver iron respond less well to interferon treatment. This is a controversial issue, even though the finding is pretty reproducible between studies. It may well be because it is people with more advanced stages of the disease (cirrhosis) who tend to get increased build up of iron in their liver as a complication of cirrhosis. This is a different situation from haemochromatosis. There have been studies to see whether attempts to remove the iron build up before treatment with interferon does improve the treatment response. Mostly these studies appear to be unsuccessful and this is not part of current practice.

Because of the probable interaction between iron and hepatitis C, if a person has both problems most specialists would feel it important to treat the iron overload problem first and then consider whether the hepatitis C should be treated. Because haemochromatosis occurs about one in 300 people, and hepatitis C occurs in about one in 100 people, it is not all that rare for someone to have both problems.

Kind regards,

Yours sincerely,

**Geoff Farrell, MD FRACP, Storr Professor of
Hepatic Medicine**

My story is also overloaded with iron

I am 50 and have had hep C since a couple of experiments with other people's donations of heroin in the early 70's. We were experimenting with everything at that time and like most of my friends, looking back, I regret nothing.

I'd already had hep A in the late 60's and later contracted a very virulent form of hepatitis B - confirmed by tests, 20 years later - while staying in the Middle East in the early 70's. This episode was contracted socially as I had no risk factors at that time, and it went away after a month in hospital.

Later I again became jaundiced after sharing a needle. It was mild and went away, but I gradually became aware that alcohol always made me very sick and I gave up drinking completely.

I have suffered general apathy for years and when hep C was discovered I figured I was an ideal candidate for it and yes, I tested positive.

Years previously, I had told a doctor I'd had hepatitis three times and was told it was not possible!

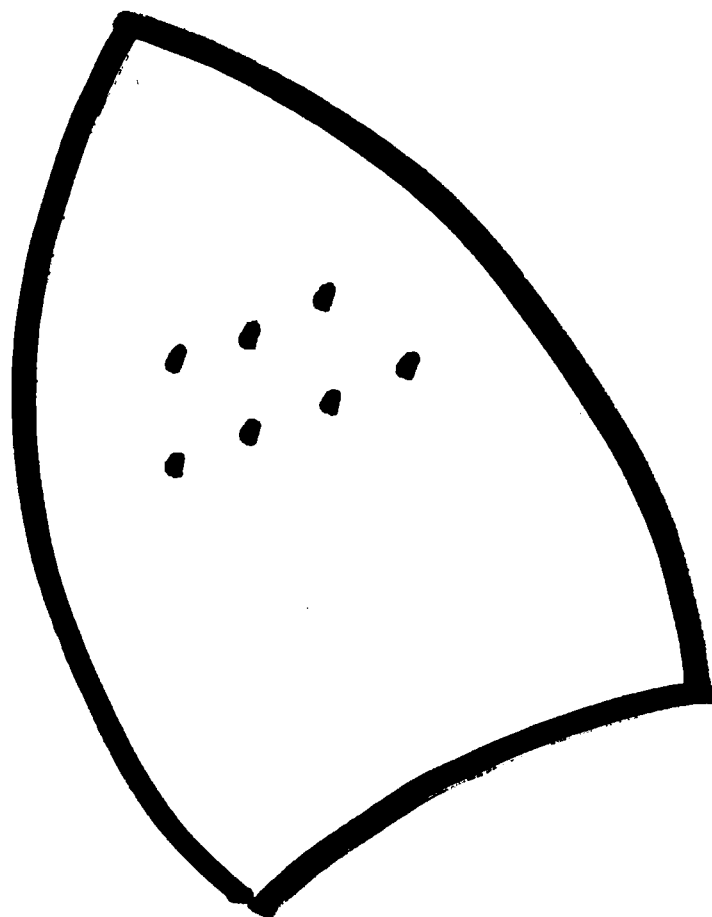
During the biopsy to prepare for interferon treatment the liver specialist discovered I also had way too much iron stored and told me I had haemachromatosis.

I had many venesections over some months before commencing on interferon as he was aware the excess iron could affect the treatment. The specialist later said I had haemasiderosis not haemachromatosis. The iron problem has not recurred but I continue to test for it occasionally.

I found that I felt so much better after getting rid of the extra iron that perhaps THAT may have been the cause of my ill-health and not the long term effects of the hep C.

My LFT's immediately became normal after I began interferon treatment and I managed to survive 10 months of hell before my LFTs shot back up. I became very sick and stopped the treatment.

My GP fortunately discovered that the interferon had "killed" my thyroid and I began hormone supplements. It had also caused my blood pressure to soar and I've had to take special pills for three years also.



Now, three years later I am still clear of the virus by yearly PCR tests. The interferon treatment was very hard to take but I was able to keep working full time by sacrificing everything else but my family and my job.

It took me at least two years to recover once the treatment finished. I work in an area of Disability Services and I see how my co-workers react if a person has hep C and I hear the comments they make. I attempt to educate them but NO WAY would I ever disclose my status to them.

Did I go through the interferon hell for nothing? My greatest relief is that it was not passed on to my child at birth.

One last thought, I live in an isolated and red neck area and find the magazine a great source of info.

Thanks, Julie

Thanks for sharing your story, Julie.

As a support organisation, we tend to hear from more people who are doing it tough. Although some of our personal stories reflect quite traumatic hepatitis C experiences, not everybody is affected this way.

Indeed, we hope that people who have not found their HCV experience troubling - or who have overcome their problems and challenges - will also write in with these stories. Like all HCV stories, they are so valuable to share.

Histologic improvement of fibrosis in people with hepatitis C who have a sustained response to interferon therapy

Annals of Internal Medicine 2000 Apr;132:517-524

Shiratori Y, Imazeki F, Moriyama M, *et al.* [and others]

The objective of the study was to assess *histological changes* [as studied under microscope] in liver *fibrosis* [inflammation] after interferon therapy.

The study was a *retrospective cohort study* [looking back on a group of people known to have been infected] involving 593 people with chronic hepatitis C who had two liver biopsies between 1987 and 1997. Of these, 487 people had received interferon and 106 were untreated.

People in the treatment group had received 2 to 6 months of interferon monotherapy within 6 months after the initial liver biopsy. The paired liver biopsies were a *median of* [most commonly] 3.7 years apart (range, 1 to 10 years). Fibrosis was staged from 0 to 4 (F0 equaling none, F1 equaling mild, F2 equaling moderate, F3 equaling severe, F4 equaling cirrhosis) according to internationally recognised scoring systems. Yearly fibrosis progression or *regression* [improvement] rates were compared between those with a sustained response (SR) to therapy, those with no SR, and the untreated group.

Of 487 people treated with interferon, 183 showed a SR. This was associated with a *mean* [average] rate of fibrosis progression of - 0.28 units/ year (the majority of people with a SR had fibrosis regression). In people treated with interferon and no SR mean fibrosis progression was 0.02 units/year. In contrast, the 106 people with no interferon therapy had a mean fibrosis progression of 0.10 units/year.

The authors concluded that regression of fibrosis is associated with sustained virological response to interferon therapy.

Comment:

This study clearly demonstrates the benefit of interferon therapy in those people who achieve a sustained response (absence of detectable virus 6 months following cessation of therapy). Among the 183 people with a sustained response, 108 showed fibrosis regression, 73 had a stable fibrosis score and only 2 showed progression. Furthermore, almost half those who had been staged as F4 (cirrhosis) showed regression, which dispels the myth that cirrhosis demonstrates "irreversible" liver damage.

Those people with a non-sustained response to interferon therapy appeared to have stabilisation of fibrosis progression, however, there was some evidence of fibrosis progression in those people with a liver biopsy more than 3 years after therapy. This suggests that interferon may provide some benefit in those people without a sustained response, but that this may be relatively short-lived.

Although people who were untreated showed fibrosis progression, this was relatively slow. A mean fibrosis progression of 0.10 units/year is equivalent to progression to the next stage of fibrosis every 10 years. Some untreated people, however, had rapid progression with 2 of 51 who had either no fibrosis or minimal fibrosis progressing to cirrhosis over the study period. It was unclear whether these two people had identifiable risk factors for rapid progression such as heavy alcohol intake.

More research is required to identify those factors which distinguish people with relatively mild disease who may progress rapidly to severe fibrosis or cirrhosis

Hepatitis C prevalence in HIV-infected patients: a cross-sectional analysis of the US adult clinical trials group

KE Sherman *et al.* [and others]. Abstract and oral presentation 116. *10th International Symposium on Viral Hepatitis and Liver Disease*. April 9-13, 2000. Atlanta, Georgia.

Although it is widely recognized that HIV positive individuals are at higher risk for infection with HCV, *data* [information] has been lacking on the true rate of HCV infection in a nationally representative HIV positive *sample* [group of people] in the United States.

Researchers at the University of Cincinnati College of Medicine have conducted a *retrospective* [looking back] study of a *demographically diverse sample* [a group made up of lots of different people] of the US population through the analysis of people in two trials sponsored by the AACTG (Adult AIDS Clinical Trials Group).

Results of the study were presented at an oral session of the 10th International Symposium on Viral Hepatitis and Liver Disease in Atlanta, USA, April 9th-13th, 2000.

Using the *HCV EIA* [Elisa antibody] test, the University of Cincinnati investigators tested the *plasma* [blood] samples of 213 patients that had been collected prior to their starting anti-HIV treatment. There were 175 men (82%) and 38 women (18%) in the sample group. The *median* [most common] age was 38 years. Seventy-six people tested positive on the HCV EIA test (35.6%). Of these people, all but 8 were PCR positive (31.9%).

Age group had a *highly significant association* [was very closely linked] with HCV infection. Compared to the other age groups, those people aged 40-49 had a significantly higher proportion (50% to 28%) of HCV antibody and HCV RNA positivity. Interestingly, neither gender nor race was significantly associated with HCV status.

Many readers want to see more highly detailed information on hepatitis C. The above articles attempt to meet this need. Although some individual research articles may appear to contradict current HCV beliefs, such scientific debate is of great benefit, leading to a better

The median *CD4 count* [an HIV-related blood monitoring test] among the HCV positive patients was 377 cells per microliter compared to 423 cells per microliter among the HCV negative patients. All of the patients with a *CD4 cell count* less than 100 cells per microliter were HCV positive, compared to 24 percent of those with a *CD4 count* greater than 500 cells per microliter.

The *mean* [average] HCV viral load in the group was 12 million copies per milliliter. Among the HCV positive patients, 58 percent had an HIV viral load greater than 100,000 copies per milliliter. Eighty-eight percent of the HCV patients had genotype 1 of the virus.

Conclusions

HCV infection appears to be significantly more *prevalent* [present] among a US nationwide risk-adjusted sample of HIV positive people than previously recognized. In the University of Cincinnati study, patients aged 40-49 years were at high risk for HCV infection, with greater than 50 percent having active HCV infection. *CD4 cell count* may be a predictor of HCV status, according to the researchers.

The investigators conclude that HCV represents "an important complication" of HIV infection. Based on the results of HCV testing of the study sample, 35.6% percent of HIV positive people in the US may be co-infected with HCV. It was suggested that broad-based screening for HCV in HIV positive patients may be warranted.

Responding to questions, Dr. Sherman (who presented the findings) noted that very few HIV-treating physicians have recommended testing for HCV infection to their patients.

Editorial comment:

The very high prevalence of HCV among people with HIV infection in the United States contrasts with an estimated HCV prevalence of around 13% in people with HIV infection in Australia. The major reason for a lower estimated prevalence of HIV/HCV coinfection in Australia is the lower proportion of HIV acquired through injecting drug use (5% versus 20% in USA). The estimated number of people with HIV/HCV coinfection in Australia is approximately 1500, which represents less than 1% of the 200,000 people with HCV infection.

For these people, however, advances in HIV therapy with resultant prolonged survival have meant that the risk of progression to advanced liver disease is emerging as a real concern. Thus, many people with HIV/HCV coinfection are contemplating the addition of HCV-related antiviral therapy to an already complicated

regime of HIV antiviral therapy, some of which has significant hepatotoxic side effects. The efficacy of pegylated interferon for people with HIV/HCV coinfection will be examined in three Australian sites, as part of a large international study to commence shortly.

- Article by Ronald Baker, PhD, originally from, www.hepcbc.org and posted on internet email list HEPV-L.

Our thanks to Dr Greg Dore, National Centre HIV Epidemiology & Clinical Research, Australia, for his editorial comment (above) and assistance in reviewing the article.

Natural history of people with persistently normal aminotransferase levels.

Gastroenterology 2000 Apr;118(4):760-4

Persico M, Persico E, Suozzo R, Conte S, De Seta M, Coppola L, Palmentieri B, Sasso FC, Torella R

Internal Medicine and Hepatology Unit, II University of Naples, Naples, Italy.

Background & Aims: Some people with hepatitis C virus (HCV) have persistently normal aminotransferase (ALT) levels and are affected by cirrhosis. This study *prospectively evaluated* [followed up a group of people over a period of time] progression of the disease in a group of HCV antibody positive people with persistently normal ALT levels.

Methods: Thirty-seven people were studied. Each subject underwent liver biopsy at *baseline* [beginning of study] and after 5 years of follow-up. At baseline, serum samples were tested for genotypes and HCV RNA load. ALT levels and serum HCV RNA were tested every other month and every 6 months, respectively. People with increased ALT were discharged from the study and treated with *interferon* [IFN]. Five years after the end of IFN therapy, a liver biopsy was performed.

Results: Liver biopsy at baseline showed chronic hepatitis in 34 patients and normal histology in 3 patients, 2 of whom were negative for HCV RNA and 1 was positive.

HCV genotypes were distributed as follows: 2a, 56%; 1b, 41%; and 1a, 3%. At the end of 7-year follow-up, 73% of the patients still had normal ALT values. Liver histology after 5 years was comparable to that observed at entry to study.

Conclusions: Most patients with persistently normal ALT serum levels have very mild chronic hepatitis. However, healthy anti-HCV positive subjects exist. In patients with HCV-related chronic hepatitis associated with persistently normal ALT levels, the grade of disease activity does not increase over years and progression to cirrhosis is slow or absent.

PMID: 10734027, UI: 20200332

- Taken with thanks from the internet email list, HEPV-L

understanding of HCV and its effect on people's health. To clarify any medical terminology, or for further information, please speak to your doctor or specialist, or phone the Hep C Helpline on 9332 1599 (Sydney callers) or 1800 803 990 (NSW callers).

I just wanted the treatment

Hello to everyone at the Hep C Council.

I am at the ripe old age of thirty nine. I have been married for three years and we have two identical twins aged three years and little Mary Christian James, aged two.

We moved from Melbourne to the West Coast of Tasmania and now after moving seven times we are waiting for a Ministry house around the Davenport area.

Whilst in Melbourne, in 1986, the Royal Melbourne Hospital diagnosed me with non-A, non-B hepatitis. Though still drinking quite heavily, I decided to go cold turkey and give it up altogether.

After countless blood tests, the Specialist Gastroenterologist talked me into having the so-called famous liver biopsy. They were very keen at the time to start me off on interferon but knocked me back because of a minor psychiatric past.

The Gastroenterologist went to meeting after meeting pushing for my access to treatment but the hospital said no. In those days it was still in the experimental stages and was very expensive for the hospital. I was on the Disability Support Pension and couldn't contribute to costs.

Monitoring my liver function tests for the next ten years, I finally got up the courage to have yet another biopsy.

A so-called doctor down here in Tasmania put my wife and I on cloud nine, suggesting that we had a good chance of receiving the combination therapy. After countless trips across Tasmania to the treatment centre and so many blood tests, I booked in to have my second liver biopsy.

The results were bad. The doctor says I have chronic hepatitis with the onset of cirrhosis of the liver. I can't help but feel angry because back ten years ago, maybe we could have stopped this virus with the interferon, thus not given the cirrhosis a chance to attack my liver.

Any rate, after my second biopsy I got the same old story. Once again I was knocked back because of my

psychiatric history. I know very well the side effects of combination therapy as it can worsen the problems of people with a psychiatric disorder.

So now the good doctors say that I've got fifteen years ahead of me! I realise all so very well that the success rate is not overwhelming but if I'd had the chance in the first place for the interferon maybe I would not have cirrhosis today.

No more liver biopsies or blood tests for me. Maybe in the near future they'll find some good medication without the torturous side effects.

By the way, congratulations on the Autumn Edition 28. I find these *Reviews* very interesting and very informative. Congratulations to everybody at the Hep C Council and good luck with the Public Awareness Campaign. The *Helpline* and the Council are the ones that have kept me alive so far.

Rodney



Thanks for sharing your story with us, Rodney.

As a support organisation, we tend to hear from more people who are doing it tough. Although some of our personal stories reflect quite traumatic hepatitis C experiences, not everybody is affected this way.

Indeed, we hope that people who have not found their HCV experience troubling - or who have overcome their problems and challenges - will also write in with these stories. Like all HCV stories, they are so valuable to share.

Although psychiatric illness still exists as an interferon exclusion point, many treatment centres do provide interferon treatment - albeit under extra monitoring and support.

Your story highlights the need for scrapping the psychiatric exclusion point and adoption of a standardised psychological assessment for all people considering treatment. Those people with current or past psychiatric conditions should be able to choose treatment with the understanding that they'll be monitored more closely and given adequate support.

Under these conditions, people need not be unnecessarily denied access to treatments.

It is believed that people with significant liver damage may be given wider access to treatments. Should this occur, we'll report it in *The Hep C Review*.

Regarding your doctor's estimate of life expectancy; many people with cirrhosis do not progress to more serious liver disease. Continuing to abstain from alcohol makes good sense by giving your liver the best chance to stay as healthy as possible.

Also see our comments to "Disillusioned" on page 30.

NSW public awareness campaign

By Stuart Loveday

On Monday 27 March, Dr Andrew Wilson, NSW Chief Health Officer launched Australia's first large scale, mass media hepatitis C public awareness campaign at the Hepatitis C Council of NSW in Sydney.

Extensively covered by news bulletins on all major TV and radio stations on the day, detailed radio and print media coverage during the following three weeks added to the campaign's main aims of increasing public awareness and reducing misinformation about hepatitis C.

Recommended by the 1998 NSW Parliamentary Inquiry into hepatitis C, this long awaited campaign served to inform and educate the general New South Wales public.

Using the slogan - "Hep C, understanding is the answer" - and key information in a question and answer format, the aims of the campaign were to:

- increase public awareness of what hepatitis C is, how it is transmitted and how big a public health issue it is
- reduce misinformation, and dispel those myths that exist in the public mind about hepatitis C
- reduce the stigmatisation and discrimination faced by many people living with hepatitis C
- create a more supportive environment for hepatitis C prevention programs.

The general feedback about the campaign has been overwhelmingly positive and all anecdotal reports to date indicate it was a huge success. The formal evaluation being carried out by the Australian Centre for Health Promotion will be available shortly, and will inform NSW Health, the Commonwealth Department of Health and Aged Care and all other state and territory stakeholders about the campaign's impact.

The NSW *Hep C Helpline*, operated by the Hepatitis C Council of NSW and whose phone numbers were

advertised on all campaign materials, took 4,250 calls during the 4 weeks of its extended hours of opening. The *Helpline* usually takes around 3,500 calls a year.

Most queries to the *Helpline* were about transmission and the outcomes of HCV infection. The majority of calls went through to the new 24 hour / 7 day a week recorded information service on voicemail - installed for the campaign itself. The Hepatitis C Council of NSW is retaining this recorded information system on a permanent basis to enable people affected and the NSW public to access summary information by phone during when the *Helpline* is not staffed.

As with any major TV campaign, some important information always had to be left out. The main complaint some people made was about the campaign's focus on current main transmission routes only. They were justifiably concerned that contracting HCV through blood transfusions prior to February 1990 was not mentioned in the TV adverts. However this information was given in all the ancillary literature and through the *Helpline*.

This medically acquired HCV information was always covered by NSW Health Department and Hepatitis C Council of NSW spokespersons in all media interviews.

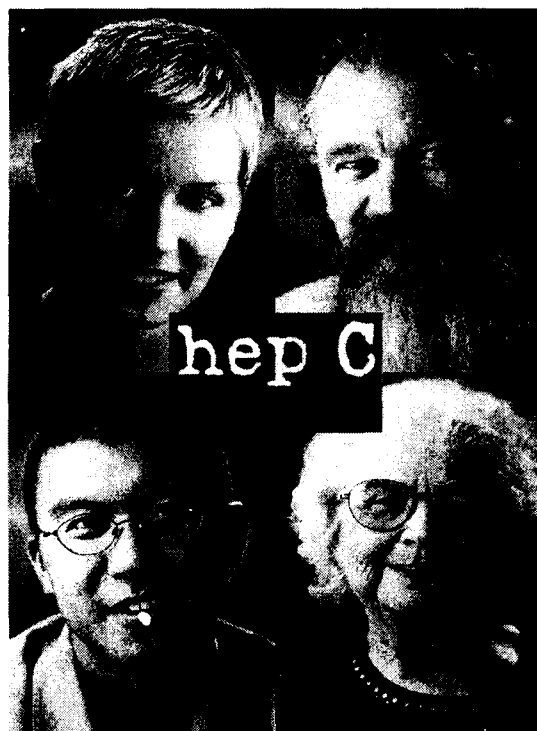
The reason it was left out of the TV adverts was based on the need to prioritise the most important aspects necessary for broader public awareness - and how hepatitis C is currently most commonly transmitted. There was insufficient time in a 30 second TV commercial to have all desirable information included.

This was billed as the world's first mass media hepatitis C public awareness campaign. In addition to the TV, radio, bus, poster and brochure advertising, many area health services carried out a big variety of innovative projects: banners across motorway bridges, coasters and beer mats, healthcare worker education seminars, tip cards, media launches (Northern Sydney's launch at Taronga Zoo

was compered by *Good News Week* identity Julie McCrossin), tattoos, fridge magnets, adverts and articles in rural papers, stalls in the main foyers of major NSW hospitals, public information nights, information resources for healthcare workers, T shirts, a market day, theme days with specific communities, peer education project activities, youth theatre and an art competition.

A major and welcome part of the campaign was the focus on HCV in communities with culturally and linguistically diverse backgrounds. NSW Health and the NSW Multicultural HIV/AIDS Service organised migrant healthcare worker education sessions, recorded information lines in community languages and ensured that ethnic print media and radio stations were well served by campaign adverts and editorial comment about both hepatitis C and B.

- Stuart Loveday is Executive Officer of the Hepatitis C Council of NSW.



Injustice of regional treatment system

Let me share a personal insight with you that highlights the injustice of our regional hepatitis C treatment system.

Three individuals consult with their rural GPs and all are confirmed as being hepatitis C positive. One is a clinical nurse specialist, another is a 70 year old pensioner and the third is a 30 year old unemployed male.

The clinical nurse specialist is now having combination treatment in the hope of clearing the hepatitis C virus.

The pensioner accessed information about treatments through her local community health centre. After weeks of consideration, she asked for a referral to a teaching hospital and was told "it wouldn't do you any good anyway" and was asked where she got her treatments information.

The 30 year old male has been told "there is nothing anyone can do".

This lack of equity is not uncommon. I feel we have shifted to an arena of treatment selection where we refer only those who we think are 'worthwhile'.

You see I am the clinical nurse specialist and it is frequently cited by my peers and others that 'people who do not pay tax should not have access to our limited resources'.

This morning we woke up to the budget and the increase in health spending for rural regions but it is not just money that we need. What we need is a passion to service without judgement and favour.

Regards, "Margaret"

A response

Margaret's is a highly significant and poignant letter and being written by the one who did get treatment it allows for an opening up of the issue of restricting access to treatment.

At present there is a restriction placed by the limited number of treatment centres offering Pharmaceutical Benefits Scheme funded (\$100) treatment. With combination therapy there is even more limitation brought on by the fact that only the larger of existing treatment centres can get the special access ribavirin.

To pretend that there is current equity of treatment access is wrong and we need to act to ensure that it does come about. ANCAHRD is trying to move things along to ensure a more rational availability of treatments to those who need it most and that will include the infected health care worker and the person with the most aggressive disease in the first instance and then others once we have the initial system working.

A fundamental problem - possibly a key factor in Margaret's situation - is that there are quite a lot of health care workers out there who do not yet understand HCV and its assessment and management. I can only presume that the person asking where the information came from and the one saying there was nothing that can be done were health care workers who are not up to speed on HCV treatments.

We have to highlight the need for more ownership of management of hepatitis C by all health care workers and we must also call for a stop to the narrow minded belief that everything would be alright if only we had more hepatologists.

We need better informed health care workers and we all need to acknowledge current treatment limitations, discussing and debating questions around the current situation:

- Should treating health care workers target treatment to more "needy" groups?
- Should we keep prescribing to a selected group of medico's or do we open things up a bit more?

Fairness is sought but it will take a while to settle it out for people with HCV

Regards, Robert Batey MD FRACP, FRCP

Director, Gastroenterology, John Hunter Hospital, Newcastle, Australia.
Deputy Dean, Faculty of Medicine & Health Sciences, University of Newcastle, Australia.

Chair - Hepatitis C Subcommittee, ANCAHRD (Australian National Council on AIDS, Hepatitis C and Related Diseases).

PCR testing

The HCV antibody blood test detects antibodies that our immune system makes when HCV enters the body. Antibodies are still present even after the infection has gone. Unlike the antibody test, the PCR test detects the actual hepatitis C virus so confirms that the infection is still present.

PCR stands for *polymerase chain reaction*. It is a type of *Nucleic Acid Amplification Test (NAAT)*. These tests detect tiny amounts of virus by duplicating the virus in the laboratory until there is enough of it to measure. Viruses contain nucleic acids as the main part of their structure.

This new cutting edge technology is pretty extraordinary considering it involves finding and measuring a virus so small that 30 billion would fit on a full stop! (*School of Mathematics, University of Sydney*).

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 which particular subtype/s of HCV a person has).

PCR viral detection test

PCR viral detection tests are mainly used as a confirmatory test when an HCV antibody test result is inconclusive. They are also used to check within the 6 month window period following a risk incident - when antibody tests are still unreliable - if a person has contracted HCV. They can also be used to determine if someone is viral positive in the event of consistently normal liver function tests and lack of symptoms.

PCR viral load testing

PCR viral load tests estimate the amount of hepatitis C virus circulating in someone's blood. It is believed that during interferon treatment, these tests will better monitor whether the therapy is working - as opposed to monitoring 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.

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 known major sub-types, interferon treatment seems to work better in 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 who are unsure whether to try the treatment or not, the PCR genotype test could help guide their decision.

Availability (diagnostic)

PCR testing has been covered under the Medicare Benefits Schedule since July 1998 (Item No. 69444) for use in certain circumstances:

- 1 Medicare covers only the basic PCR HCV viral detection test - as opposed to viral load or genotype tests.
- 2 Medicare will cover only one PCR test - each year - for any one person.
- 3 Medicare covered PCR tests are available only in limited situations - including:
 - a) people who have had a positive HCV antibody test and who have normal liver function test results on two occasions six months apart; or
 - b) people who have inconclusive HCV antibody test results; or
 - c) people who have weakened immune systems (eg. HIV/AIDS) and want to confirm whether they are hepatitis C positive or not; or
 - d) detecting acute hepatitis C, prior to seroconversion, in those people who have signs of acute hepatitis yet other causes have been excluded (eg. hep A or hep B).

PCR testing is made available in these cases where this information is considered necessary for the clinical management of the person's hepatitis.

Availability (treatment monitoring)

As mentioned above, PCR genotype and PCR viral load tests have emerged as the most useful tools for predicting and monitoring response to interferon monotherapy or Rebetrin combination therapy.

All three variations of PCR testing will soon be covered under the Medicare Benefits Schedule (under certain circumstances) but the date of effect has not yet been confirmed. It is believed that coverage will take effect some time this year.

The request for the above monitoring tests are limited to treating specialists and are for patients with confirmed hepatitis C (antibody or previous PCR) who undertake antiviral therapy depending on the result of testing.

These additional funded access arrangements allow for:

- 1 x PCR genotype test - when initially considering treatment options.
- 1 x PCR viral load test prior to therapy - should someone decide to proceed with interferon or combination therapy.
- 4 x PCR viral detection tests prior to and over a 12 month treatment/ follow up period - to help monitor treatment response.

The maximum number of PCR viral detection tests for any course of treatment is four, including any provided under Item 69444 (above).

Test limitations

Despite improvements in the sensitivity of PCR technology, it's important to assess HCV viral status on the basis of a series of PCR tests over an extended 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 so low that the PCR test won't pick it up. Thus, someone who tests PCR negative may still have a current infection.

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.



Women's health

Have you considered why health planners have taken a specific approach to women's health?

In a mainstream health system where: women generally live longer than men; more women use health services; and most health service providers are women; what is it about women's health status and their needs and role within the health system, which leads to the demand for a special focus on women's health?

The answer is partly historical and partly to do with women themselves expressing their health needs and concerns about gaps in the health care system's capacity to respond.

Over the last 20 years we have seen a strong move towards prevention in health care rather than mere reaction to illness. Accordingly, we've seen the need for accessible, people-orientated health services.

Within these changes, women's health and health issues have played a major role, both in developing the framework of alternative approaches to meet the health needs of women, and in challenging pre-existing health services for failing to meet women's particular needs.

Problems and gaps

One of the principal contributions made by the women's health movement has been to identify the problems and gaps that have existed within the health care system.

These have included:

- Analysis of health status data indicates that, although women live longer than men, on a per capita basis they have higher rates of morbidity, chronic illness and disability. In addition, their longer lives result in more aged women and increased demand for more appropriate aged care services.

- Health status has been linked to socio-economic status i.e. low income earners who have limited access to reasonable levels of housing, employment, education and transport are more likely to suffer from ill health.

Since the majority of adult poor are women, often with dependants, connections between low socio-economic status and gender suggest a need to focus on women to improve the health status of Australians in general. This is particularly so for certain groups such as Aboriginal women and women of non-English speaking backgrounds who may be isolated by cultural and language differences as well as being poor.

- Women have special health problems and health needs which are associated with their reproductive, sexual and social roles. Women assert that these have not been equitably addressed by the health system in the allocation of resources, or in research priorities.

- An overriding concern that women continually express is the failure of many health services to meet their needs effectively, and to deal sensitively with their health problems.

In the Victorian report, *Why women's health? Victorian women respond*, women widely reported concerns about the way they were treated by the health system, particularly medical and hospital services. Complaints ranged from failure to take them seriously and over-medicalisation of general health problem to attitudes of sexist stereotyping and impersonal and dehumanizing treatment. Many women stated that their experiences within the health system added to their stress as patients.

Women also expressed concern about lack of information in a form they could understand, and consequently had difficulty in participating in choices about their own health care.

The development of women's health services in various states and territories has been designed (at least in part) to meet such concerns.

- Women's pivotal role of housewife with responsibility for family health care increases their use of health services both on their own behalf, and on behalf of their 'health charges'. Some have argued that, while most adult males and children have an internal family health support system which keeps them 'well', women do not. This lack increases their levels of ill-health and means that they are more likely to need public health services to support their own health maintenance.

- Woman's health groups also have drawn attention to perceived as unnecessary medical interventions and over-servicing of normal activities such as childbirth e.g. caesarean sections have increased in recent years, yet there has been little correlation between variations in caesarean rates and reduction in perinatal mortality.

- Although women are the main users of the health system, they are not well represented in senior professional or decision making positions which affect the way health care systems are run, resources allocated, priority problem areas identified and so on. While precise figures are not available overall less than 15 per cent of significant senior positions in major health decision making bodies in Australia are held by women.

- Nearly all the unpaid health care in the community is undertaken by women. The consequences are:

a detrimental effect on their own mental and physical health. This is particularly so for women who care for elderly, disabled or chronically ill relatives, often without the support of community care services. Their situation is exacerbated if they also have to cope with rearing children, as well as full- or part-time employment. This has implications for public health policy emphasis on increased community based care for people who are chronically ill, disabled, elderly or recuperating;

after a lifetime of voluntarily caring for others, there is often no-one to care for them when they become elderly, disabled or chronically ill.

- Occupational health and safety issues have developed in response to unionised workforces acting collectively with employers, governments and health professionals. However, women are more likely to be employed in low paid, low status work. They are less likely to be in unions, or to be represented in union decision making. Where women in health unions have been successful in promoting workers' needs (e.g. Royal Australian Nursing Federation), their attention has focused on achieving equality in basic wage and work conditions. For these reasons women's occupational health and safety needs have not generally been given priority.

Listening to women

Current national health data collections in Australia are universally recognised as inadequate, but they are particularly so in relation to women.

One woman at a women's health forum put the problem succinctly:

"data currently collected on health and illness do not document chronic sadness and exhaustion"

To assess women's health needs we must look beyond conventional health status indicators as the basis for setting priorities, towards women's reported perceptions of their health needs. The primary sources within this context are women-centred research and consultation with women. Such studies show that:

- Women see their health in a social and emotional context (*'Doctor, I just feel tired all the time'*) and not just in terms of physical illness or injury. This has important consequences for the ability of health systems, geared to treatment of physical symptoms, to respond. Many women express dissatisfaction with medical responses which prescribe drugs for complaints of depression, tiredness, stress etc. without addressing underlying causes; a treatment which additionally carries risks of drug dependency;
- chronic illness, fatigue and mental stress are reported by women more than men in self-report surveys;
- health concerns are more likely to be expressed by women in the context of dissatisfaction with a health service (*'The doctor didn't take me seriously'*). Research shows that women sometimes receive a qualitatively different medical response than men to similar health problems.

Equity

Achieving equity in health for women also involves consideration of particularly at risk groups such as women living in poverty, young women, aged women, women from non-English speaking backgrounds, rural and isolated women, Aboriginal women and women with disabilities. These women can experience greater disadvantage, both through their gender needs not being met, and the special health disadvantages of their group as a whole.

Women in poverty. Health status is linked to socio-economic status. Women generally earn less than men, and are more likely to live below the poverty line. Many are sole parents, and have the additional stress of maintaining and rearing children on insufficient incomes.

Young women (15-19 years). Studies show that unemployment is linked to health status. Unemployed young people report more physical health complaints and lower life satisfaction, feel more powerless, and experience depression more than those who are employed. Young women also have added health risks associated with unwanted pregnancy and sexually transmitted diseases, and reported increases in levels of smoking and alcohol consumption.

Aged women (65 years and over). This group features in

studies of health inequalities on two major counts. Firstly, aged people generally experience more ill health than any other group. Secondly, there is a marked imbalance between the numbers of males and females, women making up a clear majority.

Aged people often lack essential social support networks. This makes coping with illness and/or disability more difficult, and limits the range of options open to them. They are more likely to be left alone when they are old and ill, and are more likely to need publicly funded care, often in institutions.

Women from non-English speaking backgrounds. In a recent survey their overall self-reported health status was poorer than that of Australian-born and overseas-born from English speaking countries. The health problem of migrant women are likely to be exacerbated by language barriers, isolation at home and unsafe working conditions.

Rural and isolated women. This group experiences particular inequities due to reduced access to the full range of health facilities available in the larger centres, problems of transport, and difficulties in accessing social support networks.

Analysis of health status data indicates that, although women live longer than men, on a per capita basis they have higher rates of morbidity, chronic illness and disability.

Lack of choice of doctors for women living in small communities means that they may not always obtain health advice and treatment in sensitive areas such as domestic violence, infectious diseases, prevention of breast and cervical cancer, menopause, or fertility control.

Aboriginal women. Aboriginal health is related to such essential services such as housing, water supply, sanitation, electricity and refrigeration. For most Aboriginal communities there is insufficient provision of these services. Adequate nutrition is also a major factor.

Access to preventive health and health care services is compounded by geographic and cultural distance from 'white' services, and inhibitions about discussing health problem. Aboriginal women tend not to view their own health independently of their role as health caretakers within communities.

Women with disabilities. This group is frequently disadvantaged by problem of mobility. This is so whether they live in an institution or at home. There is also a greater risk of poverty caused by the high costs incurred as a result of the disability, and the difficulty of finding employment. Denial of their sexuality, limited access to mainstream health services and reduced control over their lives can have detrimental effects on the health of disabled women.

- Abridged with thanks from the paper, *National Policy on Women's Health: A framework for change*. Feb 1988, Commonwealth Department of Community Services & Health.

Women, HCV, drugs and pregnancy

By Stephanie Barnes

Many of the women who present to our Drugs and Pregnancy Service are hepatitis C positive. They also have many other issues that they have to deal with including drug dependence, homelessness, domestic violence, legal issues and many other issues often related to their personal upbringing.

Regardless of whether their pregnancy is planned or not, it is often associated with feelings of guilt and fear. There may have been times when they have been judged harshly and perhaps treated badly by the health care system.

Some of these experiences may result in women not wanting to access services, hence, the failure to attend appointments - often misinterpreted as "they don't care".

This is certainly not my experience though. Most of the women who present to our service desperately want to get their lives back in order and do the best they possibly can for their baby. However, when faced with a multitude of difficulties, it can be difficult knowing how to prioritise.

In relation to hepatitis C, most women want quick, straightforward answers. Two of the most common questions asked are: "Will I pass this on to my baby?" and "Can I still breast feed?".

These questions are explained well in the pamphlet produced by Royal Prince Alfred Hospital, *Hepatitis C and Pregnancy; Hepatitis C and Children*. It says..

"Less than 10% (1 in 10) of babies born to hepatitis C positive mothers acquire the virus.

There is a small risk (less than 10%) of mothers transmitting hepatitis C to their babies at birth (this is called vertical transmission). It is not known whether the method of delivery (vaginal or caesarian) changes the risk of transmission.

Breastfeeding has not been shown to transmit hepatitis C. Mothers with hepatitis C are recommended to breastfeed their babies. If the nipples are cracked or infected, the baby should not be given breast milk until the nipple problem has resolved. Breast milk should be expressed and thrown away during this time to make sure the milk supply does not fail."

- Stephanie Barnes is a Clinical Nurse Specialist at the Drugs and Pregnancy Service, Liverpool Hospital.

Pregnancy, treatment gender and HCV

By Paul Harvey

Pregnancy

While there are few implications for a baby should the father be HCV positive - there is a risk of an HCV positive mother passing the virus on to the baby. Should a mother test PCR positive, this risk has recently been estimated at about 6%. Should she test PCR negative, the risk is believed to be "very low" (Dore G, et al. BMJ 315:333-337).

Interestingly, recent studies have suggested that a mother's viral load will increase but her ALT level will decrease during pregnancy (Gervais A, et al. *Hepatology*, 32(2):293-299).

As highlighted in *Drugs & Pregnancy* (left), mothers in particular may experience feelings of guilt should a baby be born with the virus. Of some reassurance is emerging data suggesting that babies and children may fare no worse than adults, even enjoying a possibly higher initial viral clearance rate of up to 40% (see *Hepatitis C in children*, page 30).

Treatment

Of great concern to people with HCV and treating clinicians are some of the specific side effects of current interferon mono and combination therapy. Although serious side effects exist in regard to conception, pregnancy and treatment, no other gender-specific side effects were reported to the National database (National HCV Database Project Final Report, 1999).

The database recorded the details of 2,986 persons; 30% being women, 70% being men. People vary in their response to treatment and many had only mild or transient side effects. Side effects that were reported included (in order of magnitude): Flu symptoms, lethargy, gastro disturbance, headache, emotional disturbance, depression, hair loss, skin changes, sleep disorders, *low platelet counts* [blood disorder], *neutropenia* [blood disorder] and a local reaction to the injections.

Interferon

Although interferons are naturally occurring antiviral proteins, medical treatment for hepatitis C involves much higher dosages than normally occur in the body. Because of its unknown effect on a developing baby, interferon monotherapy is not available to women who are pregnant, who are not using adequate contraception or who are breastfeeding.

Ribavirin

Combination therapy involves interferon and ribavirin. Studies on animals have linked ribavirin with birth defects. Accordingly, additional exclusion criteria apply to combination therapy. Not only is it not available to women who are pregnant and/or breastfeeding, but it is not available to anyone - women or men - who do not use adequate contraception during, and for up to six months after, treatment. This is because the drug *persists* [stays] within cells for several weeks after therapy ceases.

- Paul Harvey is Special Projects Officer at the Hepatitis C Council of NSW

A support group for medically acquired hep C



The group is open to those who have contracted hepatitis C through:

- Blood transfusions or receipt of blood products
- Mass vaccination programs
- Needle stick injury; and
- Artificial insemination

When:

First Thursday of each month

Hosted by:

TRAIDS - Medically acquired
Hepatitis C and HIV Counselling,
Support and Advocacy Centre.

Venue:

Parramatta Health Service
158 Marsden Street
Parramatta

For more info:

Sheelagh Daniels
02 9843 3143

Strengthening Partnerships: Coordinated Care Pilot Project

Greater western Sydney

Established in 1986, TRAIDS is a Statewide service that provides counselling, support and advocacy to those living with medically acquired infectious diseases including hepatitis C.

Central to our current pilot project are mechanisms to ensure that clear and easily accessible pathways of referral and care exist between general practitioners, gastroenterologists, alternate health practitioners, clients and our services.

In order that this may be achieved, we need to speak to those people living with medically acquired hepatitis C and those involved in the treatment and care process.

The type of information we are aiming to obtain includes:

- What you know about our Centre and what it provides?
- When would you refer or be in touch with TRAIDS?
- Why you would not refer to (or be in touch) with TRAIDS?
- What you would like our service to provide?

Greater western Sydney has been chosen as the geographic area for this pilot project owing to the reported concentration of our client group in this region. This area includes: south-western Sydney, western Sydney and the Blue Mountains.

Can you help?

If, after reading this overview you either want to know more or, fall within the boundaries of those people we are seeking to speak with (as either a client or professional), then please call me at TRAIDS on: 02 9843 3143.

I look forward to speaking with you soon.

Sheelagh Daniels

TRAIDS

+

Inner-city blues

Harm minimisation has a direct impact on reducing the impact that HCV and other illnesses have on our society. Other strategies have a more indirect influence, though.

In a back-street recording studio in Surry Hills, broken young lives are being rebuilt through music.

Jamie Ryan is the next Michael Jackson - just ask him.

"I'm on my way to stardom, kid!" he says, standing in the rain in a Surry Hills back street, cigarette held defiantly between thumb and forefinger. At 21 he's all attitude and defiance. The crossed-arm stance and hip-hop inflected speech are adopted from high profile rappers and adapted through eight hard years living on Sydney's streets.

I know it's out there [stardom] and this place is going to help me," he says.

"This place" is the Sydney City Mission's Creative Youth Initiatives centre (CYI) in Little Albion Street, Surry Hills, an inner-city locale that is sought out, rather than stumbled upon. Behind the heavy security grill and up two flights of stairs, people like Jamie - the "marginalised youth" described in government departmental reports into homelessness, drug dependency, mental illness or all of the above - are being given an opportunity to pick themselves up from their back alleys and refuges. When Lou Reed sang about Jenny - "her life was saved by rock 'n' roll" - he could have been describing any of the students in the Sounds of the Street (SOTS) program.

Since 1993, SOTS has taken in people aged 16 to 25 who have fallen between the cracks and put them through a crash course in music production. The bare-knuckle studio where they meet three days a week is a mixture of threadbare furniture and donated musical equipment ranging from chipped guitars to the latest music-sequencing software.

The resources are modest, but the results have been inspiring, not just to those involved in the program, but to anyone who has listened to the nine CDs the program has produced. The latest, a compilation of the first six CDs titled *The Only Limit That I See Is The Sky*, is an

idiosyncratic mix of styles - the odd folk ballad rubbing shoulders with death metal and hip-hop.

Its launch will see artists from the program on-stage alongside local musicians including Steve Kilbey, Carla Wemer and Leonardo's Bride.

Program coordinators Steve Bull and John Kilbey (Steve Kilbey's brother) are both musicians in their own right. They've also become counsellors of sorts to the kids who come through the door.

"There are two levels of success here - those who go on to become musicians and those who come and get the confidence to go and get a job," Bull says, as he waits for the current intake to arrive.

"That's really the primary aim - building self-esteem' - but it's also about building skills and creative expression."

They are, as Kilbey jokes, the "unearthed of the underclass".

"Something I've realised since I've been working here is that being homeless isn't just about not having somewhere to live, but is also about not having support from family and friends."

The scheme recruits via youth centres, refuges and word of mouth, interviewing potential students to determine who will benefit the most. Some have basic musical skills, others can barely read or write. The one basic prerequisite is a desire for self-sufficiency.

"The transient nature of the group makes contact problematic," Kilbey says. Circumstances also interfere with a student's ability to complete the course.

"We've had one guy who wrote a really good song and had only to finish the vocals. The night before, he had trouble with the law and had to split. I was disappointed, but it made me realise it was up to them."

Back in the studio it is hard not to see the child in Jamie, especially when his energy fluctuates and swings so frequently. He parades around the room giving a high voltage freestyle rap performance to anyone who will listen, then slumps, head down on a couch, silent, yawning and red-eyed. When he raps, Jamie is lucid and demonstrates a real talent for rhyme, rhythm and expression.

"I've always had to be the man of the house - rap's kept me strong, helped me be up and support my Mum," says Jamie, back outside for a smoke after laying down some fresh freestyle to a hip-hop track. I was never able to be a child, I had to be the man. It's not her fault, it's just the way it was."

After his methadone-addicted father left the family, Jamie's life became textbook urban dysfunctional. He was involved in a gang in the Parramatta area, was homeless at 13 and began suffering bouts of depression - "from constant failure and trying to please my Mum" - by the time he was 18.

He hasn't seen his father in several years, nor does he want to.

"My mother had traumas through her life and was always an angry person. She'd go off at me, I'd go off into my room and play rap. I can't stop; I

like to be cocky. A lot of men have made her sad in her life. She told me once she had big expectations for me. This is something to give back to her - I don't want her to think she was a failure.

"I've come to terms with it all. I've been taking it slow, but it's going to work."

Among the rappers he emulates -Busta Rhymes, Ice-T, Run DMC, Public Enemy and Tupac Shakur - Jamie looks up to artists who have come through the program and have continued making music with some success.

Among them is Lez Bex, 21 years old and a 1998 graduate. Originally from Cunnamulla in Western Queensland, Lex is a guiding light for many of the students. He has recorded five tracks through SOTS, has been involved in several other projects and performances and is recording a debut album at the Community Youth Initiatives studio.

His music reflects "everyday living from someone without much".

"I've had a great life, but a prick of a life as well," he says. "There have been lots of challenges, but I use those as a learning facility instead of a downfall."

Homeless for almost 12 months before he joined the program, Lez spent about nine years living on the streets. He has also spent time in prison.

"It's something you get over," he says. "Other people have it much harder than you do."

It's a positive approach mirrored by Jamie and his classmates who have assembled in the studio to work on a track.

Matt, 24, has been on methadone for the past three years.

"This is a good outlet. If you are using drugs, it does take the place of that. Boredom is a big thing - using for a while was great, but it hasn't been for a long time. I can't convince myself it's fun. It's nice, like a hot shower, but ..."

He says he is also interested in the scriptwriting course, one of many creative projects the centre offers.

Ex-student Bobby D, a 23-year-old drug-user who was diagnosed with schizophrenia, drops in.

"If it hadn't been for this course, a lot of people would be fucked. I came out of a psych ward straight into this place. I left and fell apart again. Rehab can detox you, but leaves you at square one. This place can take you to squares three, four or five."

As he speaks, 18-year-old Josh Moala records a Barry White style vocal he has written. He skipped court last year - "taxi assaults, rolling people, a few robberies,

nothing big" - and returned to his native Tonga. On returning to Australia, Josh handed himself in and is now on the straight and narrow.

"It worked out for me. At least I didn't have to see the inside and I've got a clearer state of mind."

Josh says he hopes the course will enable him to record music with his gang, FOB.

"Our studio is a back lane - when we drink up, we sing and jam," he says. "We're natural street kids; it's in our blood. And it's natural for Tongans to fight, but we're going to fight through our music."



At the end of the day, the SOTS organisers are philosophical about the role they are playing

"We are dealing with people the education system has failed, some who would find it difficult fitting into other places. For us it is about giving a positive experience to people who haven't had many positive experiences," Bull says.

- Abridged with thanks from an article by Nick Leys in the Sydney Morning Herald supplement, *Metro*, 31/3/00.

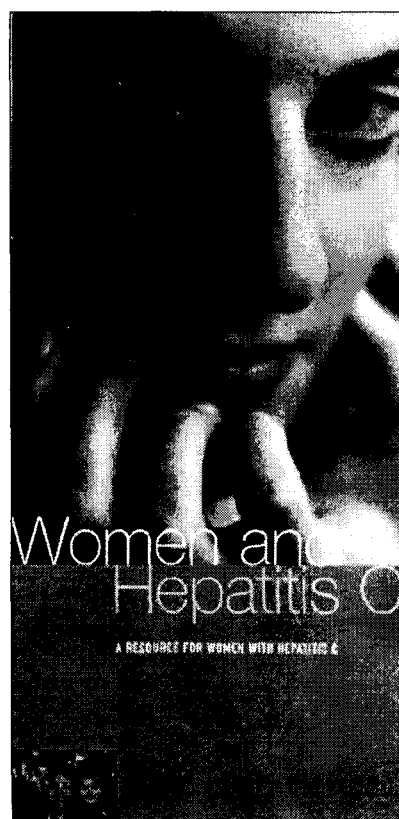
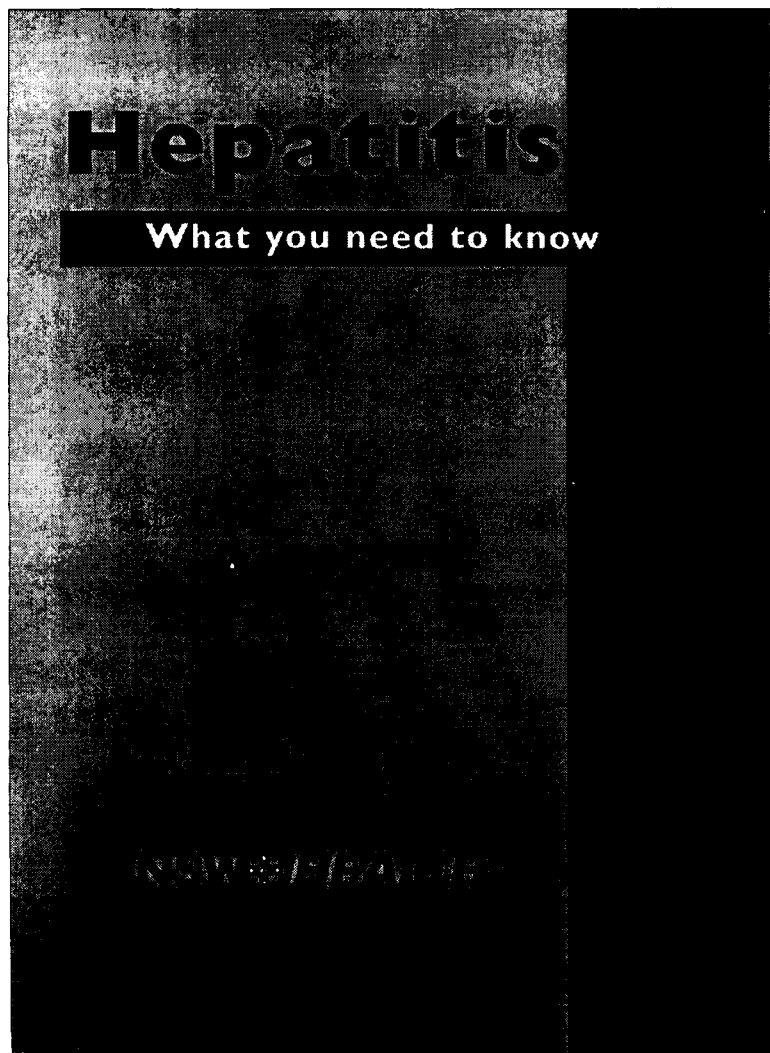
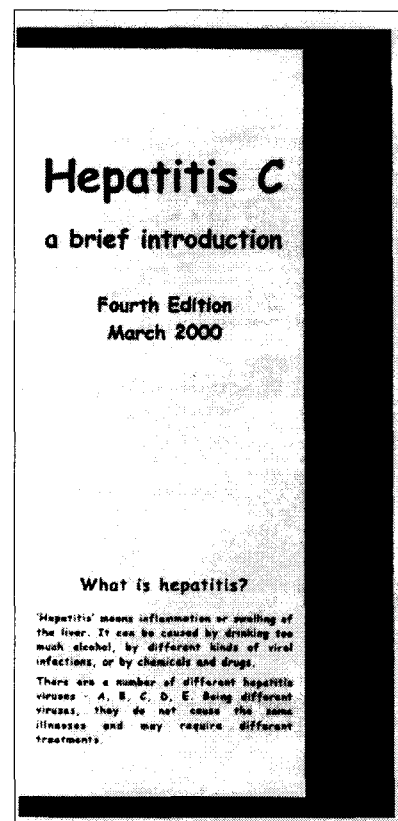
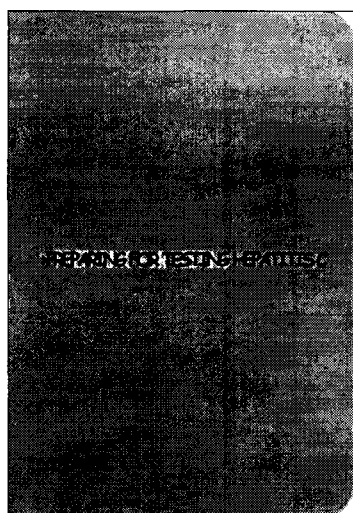
Nick Leys is a reporter with the Sydney Morning Herald.

New resources available

Pictured clockwise from right are a range of new and revised information resources:

- *Preparing for testing: hepatitis C*, a new booklet produced by the Australian Hepatitis Council (AHC) and the Australian National Council on AIDS, Hepatitis and Related Diseases (ANCAHRD)
- *Hepatitis C: a brief introduction*, 4th edition, the latest revised version of a generalist HCV brochure produced by the Hepatitis C Council of NSW
- *Women and hepatitis C*, a new booklet produced by the AHC and ANCAHRD
- *Hepatitis C: what you need to know*, 3rd edition, the latest revised version of a detailed HCV information booklet produced by the Hepatitis C Council of NSW.

For information on availability, contact the NSW Hep C Helpline (see page 42) or the Hepatitis C Council in your state or territory.



Men's health

Have you considered why health planners take a specific approach to men's health?

As members of the NSW community, all men are able to access a range of public and private health services, including general practitioners, community based services and hospitals. However, there is strong evidence that women utilise existing health services more often and more effectively than men. In addition to published data concerning general health, trends exist within HCV health services with proportionately more women accessing the NSW Hep C Helpline, yet of NSW HCV notifications, men outnumber women at a ratio of nearly 2:1.

According to Medicare data, gender access to medical practitioners is almost identical between boys and girls up to age 14. From age 14 to 44 women access medical practitioners at a much higher rate, largely explained as being due to issues concerning contraception and child birth. However, beyond age 44, the differences persist.

Being male or female influences our understanding and experience of health, how we use health services and our ultimate health outcomes. Gender also influences the decisions made by those responsible for providing services. Gender-based inequalities in health for women have been acknowledged by policy makers and health service planners since the mid 1980s. It has only been in recent years, however, that inequalities in health outcomes for men have received attention and gender based issues examined for potential solutions.

Why men?

In general terms, men in NSW die at higher rates than women. Heart disease and cancer occur more frequently in men than in women at all ages, and until very old age, men have the overwhelming majority of accidents and injuries. Men also consult doctors less frequently for all health causes except injuries.

There are suggestions that men may ignore or not recognise symptoms of ill health and delay seeing a health care practitioner, while women may acknowledge the same symptoms and take action sooner.

There are also strong *correlations* [links] between family income and health, showing that low income families have higher death rates than their high income counterparts. Low income men have the strongest *associations* [links] with high mortality rates.

In addition, health risk behaviours like smoking, drinking and risk taking behaviours on the sporting field, in the workplace or on the road are heavy contributors to men's poorer health status.

Sex and gender

Being male or female is not only a biological state - known as sex. It occurs within a social and cultural context with strong perceptions of what is 'male' and what is 'female' - known as gender.

Moreover, different social and cultural contexts arbitrarily ascribe different values or behaviours to masculine or feminine genders. These values vary from culture to culture and within a culture. For instance, what is considered necessary 'masculine' behaviour for a twenty five year old firefighter may not necessarily be seen as such for a fifty five year old accountant.

Perceptions of what is masculine and feminine have the potential to be either beneficial or detrimental to health behaviours and health outcomes. For instance, in line with contemporary Australian expectations of masculinity, a man might participate in beneficial health behaviours such as regular physical activity, or detrimental ones, such as excessive alcohol use.

These issues should be considered of significant interest to men within the general community, in regard to ownership and responsibility for personal health. They should be of great interest especially for men with any type of chronic illness.

In conjunction with initiatives at a Commonwealth level, NSW Health has developed an initial discussion paper, *Strategic Directions in Men's Health*, and the policy framework document, *Moving Forward in Men's Health*. Both are available from the NSW Health website.

In recognition of the need to educate and to raise awareness amongst health professionals as to the unique needs of men and ways to tailor services to men's needs, the Fremantle Regional Division of General Practice developed a training video for GPs, Where Have All the Fellas Gone?

The video encourages GPs to take a holistic approach to male patients and ways to approach key health issues affecting men's health.

- Abridged with thanks from *Moving Forward in Men's Health*, NSW Health, June 1999.



Sexual transmission of hepatitis C: what is the evidence?

By Dr Gregory Dore

A recent article in *The New England Journal of Medicine* first authored by Dr Miriam Alter, the chief hepatitis epidemiologist [disease transmission researcher] from the Centers for Disease Control and Prevention in Atlanta, USA, claimed an *independent association* [a linking factor, in its own right] between hepatitis C infection and number of lifetime sexual partners (Alter M et al. NEJM 341:556-62, 1999).

It also claimed that 20-25% of all hepatitis C infections in the United States were acquired through sexual contact.

The study, a random household survey, involved interviews, physical examination, and collection of blood specimens to assess the health and nutritional status of Americans - hepatitis C was only one of numerous diseases evaluated.

Among adults, hepatitis C prevalence was 1.8%, with independent associations including education level, poverty index, marijuana use, cocaine use, number of sexual partners, and age at first sexual intercourse.

The study collected extensive data, but failed to ask the crucial question of "have you ever injected illicit drugs?".

The authors were happy to acknowledge that having the odd joint or bong was not a biologically plausible explanation for transmission of hepatitis C, [when saying that] "marijuana use serves as a surrogate for other methods of transmission (such as injection-drug use and high-risk sexual practices)."

However, there is a much more obvious form of "surrogacy" represented by their results - it is likely that most, if not all, of the factors associated with higher levels of hepatitis C prevalence (poor education level, poverty, cocaine use, increased number of sexual partners and early age of first sexual intercourse) were also strongly associated with injecting drug use.

In a letter responding to their article we stated that the apparent association between hepatitis C and number of sexual partners was an example of *epidemiological confounding* [something that skews or distorts a research study] (Dore G et al. NEJM 341:2093-4, 1999). In particular, it is likely that people reporting a higher number of sexual partners were, as a group, more likely to have a history of injecting, than those who had few partners.

We argued that even in other studies where the question "have you ever injected illicit drugs?" has been asked, people are often not willing to answer correctly.

In an environment such as the United States, where drug use in general, and injecting, in particular, are highly stigmatised, it would not be surprising to see substantial under-reporting of injecting drug use. We also outlined the evidence against significant levels of hepatitis C transmission through sexual contact.

So, what is the current state of evidence around sexual transmission of hepatitis C?

An examination of this evidence is essential in order to inform a person with hepatitis C and his or her partners about the risk of sexual transmission, whatever that risk.

On purely biological grounds, it is plausible that hepatitis C could be transmitted sexually.

Although semen and vaginal secretions themselves probably contain little, if any, hepatitis C virus (Caldwell S, et al. Liver Trans Surg 2:124-9, 1996), sexual contact may well involve some degree of blood contact, for example, if sex takes place during a woman's menstruation, or involves some degree of trauma.

It is another matter altogether to demonstrate that sexual transmission of hepatitis C actually occurs, or if it does, that it occurs with a sufficiently high probability to be of concern to people with hepatitis C and their partners.

Several types of studies have been used to investigate the sexual transmission of hepatitis C:

Case series

Cases of people diagnosed with hepatitis C, self-reporting how they felt they contracted the condition.

Although a high proportion of cases are associated with a history involving the potential for blood contact, predominantly through sharing of injecting equipment, cases without such a history may be attributed to sexual transmission.

In the United States, 20-25% of people with acute hepatitis C are considered to have acquired their infection through sexual contact (Alter M and Moyer L. J AIDS 18(suppl 1):S6-S10, 1998). Many of these people give a history of sexual contact with a person with hepatitis C, but deny other risk factors such as sharing injecting equipment.

In contrast, among a series of 467 people newly diagnosed with hepatitis C from the north coast of New South Wales, all but one reported actual or potential blood exposures (injecting drug use, 85%; pre-1990 blood transfusion, 6%; blood exposures, 8%). None of the cases reported sexual contact as their only possible exposure (Sladden T, et al. MJA 166:290-293, 1997). Of 54 partners who tested positive for hepatitis C and were questioned about risk factors, all had potential blood exposure.

Why the disparity between studies in the United States and Australia, in settings where, presumably, sexual behaviour and practices are quite similar?

Under reporting of injecting drug use is the obvious explanation.

Although injecting drugs undoubtedly is stigmatised in Australia, in the United States there is almost certainly greater stigmatisation of illicit drug use. Hardened sentencing for drug-related crimes in recent years, and a general mistrust of those in authority, may have also contributed to greater under reporting of illegal activities. In contrast, the north coast of New South Wales is probably an area where stigmatisation of drug use is relatively low, and trust of researchers and those in authority may be relatively high.

The study collected extensive data, but failed to ask the crucial question of "have you ever injected illicit drugs?"

Prevalence in people at sexual risk

Certain population groups are recognised as being at higher risk of sexually transmissible infections, and would be expected to have higher rates of hepatitis C if it was indeed sexually transmissible.

Female sex workers and homosexual men are probably the groups most often considered in such studies, which have generally not found increases in the levels of hepatitis C that would be consistent with an agent that is readily sexually transmissible.

In a study among gay men in Sydney (Bodsworth N, et al. *Genitourin Med* 72:118-22 1996), although the prevalence of hepatitis C (7%) was considerably higher than estimates of the general adult male population prevalence (2%) (ANCARD 1998), there was no association between hepatitis C and either number of sexual partners or sexual practices. The higher rates of injecting drug use, and not sexual behaviour, among Sydney gay men are almost certainly the explanation for this higher hepatitis C prevalence.

Cross-sectional partner studies

Several studies over the past decade have found that the spouses or regular sexual partners of people diagnosed with hepatitis C have higher levels of hepatitis C than found in the general population. The prevalence in partners has also been found to be related to the duration of the sexual relationship. Such studies, based on testing at one time point, may suggest transmission associated with stable partnerships, but whether it is sexual contact, other forms of contact involving blood, or a common antecedent history such as unsterilised medical injections in both partners is difficult to establish.

Longitudinal partner studies

The most convincing evidence for or against sexual transmission should come from longitudinal partner studies, in which one member of the couple is known to have hepatitis C at the start, the other is known or can be assumed not to be infected, and forms of blood contact not involving sex can be convincingly excluded. So far, very few such studies have been reported. Two studies of the sexual partners of several hundred women infected through contaminated anti-D immunoglobulin injections given following childbirth in 1977-1978, in Germany and Ireland and with average duration of relationships of 10-15 years found no cases of probable sexual transmission (Meisel H et al. *Lancet* 345:1209-11, 1995; Power J et al. *Lancet* 344:1166-7, 1994).

What does an examination of these studies deduce with respect to sexual transmission of hepatitis C?

If the question is "can hepatitis C be transmitted through sexual contact?" then the answer almost certainly is yes.

If the question is "what is the level of risk of hepatitis C transmission through sexual contact?", then the answer is extremely low to negligible.

Are there circumstances in which sexual transmission may be more likely? The answer to this question is based on plausibility rather than direct evidence, but, circumstances in which blood contact is more likely, such as sexual contact during menstruation, involving traumatic sexual practices and in the presence of genital ulceration, may introduce a significant risk of sexual transmission of hepatitis C.

And finally, but most importantly, what advice should be given to people with hepatitis C and their sexual partners?

My advice is that for people in stable relationships, condoms are not necessary. Although I believe menstruation (whether the female or male partner has hepatitis C) to be a low risk setting for sexual transmission, either use of condoms or abstinence from vaginal sex is probably a reasonable policy. With regard to sexual contact with casual partners, my advice would be that condom use is sensible, more for protection from other truly sexually transmissible infections.

- Dr Gregory Dore, Lecturer in Epidemiology, Infectious Diseases Physician, National Centre in HIV Epidemiology and Clinical Research, University of New South Wales.

Abridged with thanks from the fully referenced original in the *Australian Hepatitis Chronicle*, Issue 4 March 2000: 2-5.

+

Disillusioned

I'm back in Australia for a month and I thought I'd write in and tell you all of my experiences with interferon/ribavirin therapy!

I am in deep denial of it all right now so I don't want to talk about it or think about it, but a letter won't kill me. And after all, the Council and *The Hep C Review* have been so supportive - and it's a comfort to know you are all out there if I ever need you.

Well, I was living with my boyfriend in Europe. I didn't leave him when I found out he was hep C positive. I was fine about it but everybody else drove me crazy. I loved him then as I do now and a teeny weeny little virus wasn't going to change that.

But the virus is one thing!
The therapy is another!

He and I didn't agree on anything! We had completely different attitudes. He decided to have complete faith in medicine and trust in the doctors.

I almost had a breakdown. How can you possibly be so trusting? So we didn't agree on the doctors.

I asked around and wanted the doctor with the best reputation. He only wanted the one he knew. Great!!

Anyway, I didn't have the right healthy attitude that I should have had so I left him to do the therapy as he wanted - and I came to Australia.

He had no support from anyone. His hair fell out - even his body hair. He had all sorts of skin problems ... nobody showed any understanding or compassion.

I wasn't going to be around because I couldn't bear the thought of the injections. He was having daily doses. I can't remember exactly what, but it was the highest dose legally permissible. What a joke.

I got a phone call from my boyfriend - from a mental institution. The psychiatrists called it an

"anxiety reaction" but simple folk call it "he went mad". So I caught the first plane back and I got him out of the mental institution. I was the only one capable of understanding that the high dosage poisoned him!!

It was awful. The doctors finally accepted that the dosage was toxic and his body had to recover from the poisoning.

All this was a year ago, exactly. Since then, we have been married and we have decided not to bother with therapy. I feel very guilty that I can't be supportive but I can't bear the thought of going through something like that.

We can't all be strong always. He hasn't even been for tests since then because we don't see what choices we have. I don't know about the future but ribavirin for me is *The Enemy*.

So are all the doctors. I won't go as far as to say the whole medical system, but I have been traumatised by the medical profession's lack of humanity. I am repelled. Didn't they see a human being? It's so obvious that doctors take advantage of some situations!

Oh well, that's the experience of a wife who does not have the virus but who loves a man who does.

God be with us all
Name Supplied



Thank you for sharing your story with us. You have both endured a very hard HCV journey.

As a support organisation, we tend to hear from more people who are doing it tough. Although some of our personal stories reflect quite traumatic hepatitis C experiences, not everybody is affected this way.

Indeed, we hope that people who have not found their HCV experience troubling - or who have overcome their problems and challenges - will also write in with these stories. Like all HCV stories, they are so valuable to share.

Treatment side effects can be considerable. Of over 2700 treatment cases reported to the Australian national database, nearly 200 people ceased treatment early, primarily due to side effects (depression and emotional disturbances most commonly cited).

It sounds like your husband may have been on a 'loading dose' trial - this involves some people in the trial initially taking higher doses, sometimes more often.

We fully support your view that everyone on trials - and undergoing standard treatment - should be given good monitoring and support. As you also highlight, medical care should be sufficiently considerate to people's personal and emotional needs.

Inside stories

Jackie Dent reports on an unusual radio show giving voice to prisoners across NSW.

Annie is halfway through her rendition of a Cranberries' tune when an enormous siren drowns her out. It is known as the muster call, when the women at Emu Plains Correctional Facility must go to a designated area and answer to their name.

This is the first time the 21-year-old, jailed for armed robbery, has sung for the 2SER-FM *Jailbreak* team. Annie, with the word "freedom" tattooed on her wrist, is nervous, but Lyn Bond and Ian Coombe, the producers of the weekly radio show, urge her on.

Her voice is beautiful. She has chosen to perform *Zombie*, a song she used to sing to her friend Davo, who has since been released.

"You used to make me sit there every single night and sing it for you, so I'm going to sing it for you again, and I wish you all the best, and I'm so glad you got out," says Annie before playing.

For the past hour, the *Jailbreak* team has been recording songs performed by Tracy, Mickey Dee and Lavinia under the watchful eye of a prison guard.

Tracy has performed in pubs and clubs and is the most energetic of the group, carrying with her an extensive songbook of guitar chords.

Jailbreak has been going into NSW jails since 1997. While the show focuses on performance, it also aims to convey health messages to jail inmates. Lyn Bond is co-ordinator of the Prisons Relationships AIDS and Infections Diseases project, funded by the NSW Department of Health, and she says there's a huge problem in jails with hepatitis C, which is transmitted through sharing makeshift tattoo equipment and drug use.

The program began broadcasting on Radio Skid Row, but moved to 2SER in early 1999 to raise its profile. Bond says that men tend to write poetry and women tend to sing, and the themes revolve around addiction, separation from family and love.

The material can be confronting. Dan, a regular contributor to the show, sings about delusions, having schizophrenia and cutting off heads.

"It is special for them," Bond says. "They feel it connects them quite often with the rest of the world, so people don't see them as being hidden away. If they can record their music and their poetry and stuff, it's kind of a connection with the world," she says.

Jailbreak airs on 2SER-FM 107.3 on Thursdays at 7pm.

- Jackie Dent is a journalist at the Sydney Morning Herald.

Reprinted with thanks from the Sydney Morning Herald's supplement, *The Guide*, 10/4/00.



What can doctors expect from patients?

Doctors play a key role in ongoing monitoring of a person's hepatitis C and the long-term maintenance of their good health.

This is part three of a four part series outlining the responsibilities and rights of both 'patients' and doctors.



Full disclosure by people of all data pertinent to their presenting health problems.

Only with full information can a doctor request certain tests, make a diagnosis, and recommend treatment in an intelligent and informed way.

Have adequate time for a full evaluation and necessary tests before making a diagnosis or starting therapy.

When you call for an appointment, your doctor may be booked up for days in advance. You will be scheduled for a time that will allow a full evaluation to be done. It is unfair to yourself and to other scheduled patients to demand to be seen sooner. If you have severe pain or

serious symptoms, let the doctor's office know and you will be seen as an emergency. Tests or follow-up visits may be scheduled up to a few weeks in advance. Before the test results are in, your doctor may not have enough information to make a diagnosis or start therapy; it takes time to receive test results.

Prompt notification of worsening or change in symptoms, reactions to medications or other health-related items.

It is often impossible for your doctor to predict in advance any adverse side-effects or directions your illness may take. To ensure appropriate therapy and treatment, you must maintain a good line of communication with your doctor.

Act professionally in the best interest of the patient.

Sometimes, what you want and what your doctor thinks is in your best interest are different. Don't expect your doctor to do something that they feel is morally wrong, professionally compromising, or illegal, or which they feel may harm you. If such a conflict arises, it is usually best for your doctor to withdraw from your care or for you to find another doctor whose ideas are more in line with your own.

Withdraw from the care of a patient with whom a personality conflict or emotional involvement exists or who refuses to follow recommendations.

Doctors can experience feelings of anger or unresolvable personality conflicts with patients. Doctors may also feel they are becoming too emotionally involved in a case or are unable to deliver care objectively. Noncompliance by people may also cause feelings of frustration and anger which may make it impossible for a doctor to deliver good care. Doctors have the same rights as a patient to end an unsatisfactory relationship which no longer serves either party. If, however, doctors decide to end a clinical relationship, they should offer to arrange for continuing care by another doctor for urgent problems, at least temporarily, and make available all relevant medical records.

Efficient use of time.

Doctors schedule people closely and often are heavily booked. Just as you would expect someone visiting you for a specific reason to come prepared, you should organize your thoughts, think about the specifics of your symptoms, and carefully write down your questions about your problem. Not only does this make time spent with the doctor more efficient, your thoughts and questions are also organized, and you are more likely to gain a better understanding of your illness. You will remember more of what your doctor tells you and will make fewer phone calls between visits for clarification.

- Adapted with thanks from a US based original, taken with thanks from the internet email list, HEPV-L



A stateside hep C story

Hi everyone in Australia. I wonder if you can relate to my story here in the States.

I found out about my hep C after having my gall bladder removed in March of '95. The surgeon called me in on my post-op visit and calmly told me that I had "Chronic Active Hepatitis C".

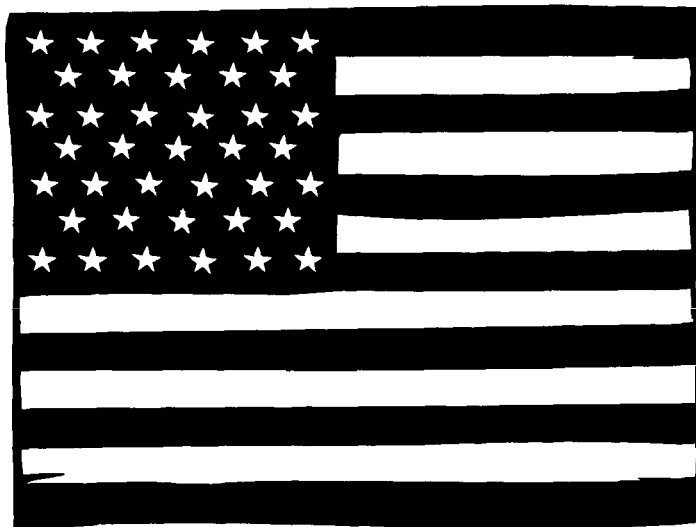
I asked "What does that mean" and he said I should just follow it up with my physician and said not to worry about it. When I came home and told my wife, who is a nurse, she couldn't believe the surgeon told me not to worry about it.

Well I followed it up with my doctor and he also seemed very unconcerned about the whole thing. He said we would monitor my liver functions and that there really wasn't much that could be done. My wife however was very concerned.

I contacted the American Liver Foundation and asked them for a list of specialists in the metro Detroit area. I received a list of names and most of them were at the University of Michigan hospital in Ann Arbor. I went ahead and made an appointment with a Dr MacDonald. He ran the test and confirmed the diagnosis of hep C and offered interferon (3x3). At the time it was my only offer and I decided to try it. We started the shots and my enzymes lowered. Shortly after starting the interferon Dr MacDonald left and went back to Australia.

My case was turned over to a Dr Grace Su. We continued the interferon for a total of 6 months before I quit because the cure was far worse than the disease. Even though my enzymes had dropped I was categorized as a non-responder because I didn't finish the entire 48 weeks of treatment. There were no other research protocols that I qualified for and I am still not receiving any treatment.

I have switched to Dr. Stuart Gordon at Beaumont Hospital in Royal Oak. He is supposed to be one of the top ten hep docs in the country. He has offered me a protocol for combo therapy for interferon non-responders. I am very leery of the combo treatment.



People on the list have said how devastating the sides can be. I can't afford to be off work for a year to do the treatment. I am also asymptomatic right now and really see no pressing need for doing a treatment that will make me feel worse than the disease.

After my case was turned over to Dr Su my work changed putting me in front of a computer all day. With internet access I started surfing trying to find out as much as I could about my hep.

I found the HEPV-L email list and several other very informative sites. I started reading all of Peppermint Patty's info posts. I found Dr Gordon after reading some of his clinical abstracts. Now I am so well informed that I scare a lot of doctors.

When I first saw Dr Gordon he was amazed at the depth of my knowledge about the available treatment options being developed. My doctor recently told me I was diabetic. By the time I was in for my second visit following diagnosis I was telling her what treatments I would like to try. Again I had gathered all of my information from the internet. I even faxed her some articles exposing the link between hep C and diabetes (*also see page 8*). She said they made her look like a hero at one of her clinical practices as she has since seen three other patients like my self, recently diagnosed diabetics that also have hep C.

I hope my story helps. It is appalling the lack of knowledge in the US health care community at large about hep C. I think this really shows in the lack of research funding by the government and allowing companies like Schering Plough to make a fortune off of the combo treatment that really doesn't even work half of the time.

Regards
Jess, Southfield, USA

Thanks for sharing your story with us, Jess.

As a support organisation, we tend to hear from more people who are doing it tough. Although some of our personal stories reflect quite traumatic hepatitis C experiences, not everybody is affected this way.

Indeed, we hope that people who have not found their HCV experience troubling - or who have overcome their problems and challenges - will also write in with these stories. Like all HCV stories, they are so valuable to share.

Surfing the net can be a rewarding experience - discovering information of interest and sharing personal stories and situations. But because of the wealth of information - some accurate, some not so - the internet can be confusing and frustrating.

For more information on surfing the worldwide web, see "Worldwide websites" on page 36 of this edition. Also see articles in Ed24, p30 and Ed23, p6.

Hepatitis C in children

By Dr Stuart Dorney

The world-wide prevalence of hepatitis C among children is between 0 to 0.2%.

Children have acquired hepatitis C by *vertical transmission* [during birth] from their mothers, from intravenous blood products and from injections with unsterile needles. In Australia and New Zealand the most common form of acquisition of HCV by children today is vertical transmission. Prior to blood product screening for hepatitis C, which began in 1990, the most common source of hepatitis C for children was medical blood products. In some countries in the world where needles are used repeatedly to give injections such as immunisations, this is the most common form of acquisition.

Blood acquisition

Donor screening for hepatitis C antibody began in Australia in February 1990. Since then there have only been a few cases of hepatitis C transmission by blood products. In these cases it was due to errors in the blood screening process.

Prior to 1990 the children who acquired hepatitis C were in groups who received multiple blood transfusions. These were children with *thalassaemia* or *haemophilia* [blood disorders], cancer, congenital heart disease and *renal* [kidney] failure. Prior to 1990 the *sero prevalence* [prevalence as determined by blood test] of hepatitis C in thalassaemic children was 40-60%, in haemodialysis 15%, open heart surgery 5% and cancer 5%.

Vertical transmission

For the future, vertical transmission will be the most common form of transmission in children. Thankfully this is fairly low.

In mothers who are viremic at the time of delivery (ie. they are HCV RNA positive) the incidence of transmission to children is about 5%. If the mother is HIV positive as well as HCV RNA [PCR] positive the risk rises to 35%. No other factors have been shown to give increased risk of hepatitis C to children of hepatitis C positive mothers.

In particular breastfeeding has not been shown to be a risk factor. The time of transmission risk appears to be at delivery.

When testing babies of hepatitis C positive mothers for hepatitis C it has to be remembered that babies receive hepatitis C antibody passively via the placenta and thus are antibody positive at birth.

In fact most babies under one year of age who are HCV antibody positive are not infected [PCR positive]. This passive maternal antibody can persist in the baby's serum for up to 18 months. Thus testing babies under this age for hepatitis C can only be reliably done if one tests for HCV RNA.

The current recommendation for testing children of hepatitis C positive mothers is that if the child is well and has normal liver function is to wait until after 18 months of age. However a case can be made for mothers who are known to be HCV RNA positive at the time of delivery to test their children at 2 to 3 months of age but only by HCV RNA. It is not cost effective to test all children.

Infection outcome

What happens to children infected with HCV? The only data available relates to children who acquired HCV from blood transfusion or blood products prior to 1990. Around 60% suffer a chronic infection but the majority are asymptomatic. The *serum transaminases* [ALT] are normal or only mildly abnormal in most.

In a small number of children who have had liver biopsies performed the microscopic changes have been minimal. It is not known how many children will develop cirrhosis. With vertical transmission long term data is still awaited but some children have been documented to lose HCV RNA after 2 to 3 years.

Treatment

Regarding treatment of hepatitis C in children, there is not a lot of data available. In the studies that have been done the numbers have been small and there are few controlled studies. Based on this limited data there is an early response and a sustained response to interferon equivalent to the response seen in adults for transfusion related infection.

There is no data yet of combination therapy of interferon with Ribavirin. There is no data on treating children who acquire hepatitis C via the vertical route. Hepatitis B is not an exact analogy but interferon treatment for vertically acquired hepatitis B does not appear to be effective.

What will we see in the future regarding hepatitis C in children? We will be following children who are infected vertically to see what happens to them in the long term. New treatments may become available.

- Stuart Dorney is Head of the Hepatology Unit, New Children's Hospital, Westmead, Sydney.

This article is from research presented at the Second Australasian Conference on Hepatitis C, Christchurch NZ, 17-19 August 1999.

A personal experience

At the age of 36 years a former partner contacted me and informed me he was hep C positive. I was very supportive but wondered why he was telling me this. I was aware that hep C was not supposed to be sexually transmitted and I had not seen him for more than 10 years.

I didn't give this any more thought until I returned to work after having had three children. On my return to work I found that I was extremely tired even though I'd had plenty of sleep.

After several trips to my doctor I finally asked to be tested for hep C - I told him about the call from my ex and we explored any other possible risk factors of which I had none. We did not think that the test would come back positive but it did.

I was devastated. All of the experts found it hard to believe as well so I was re-tested and re-tested. It was thought that there might have been an occupational exposure somewhere along the line.

Who cared how I got it? I had since given birth to three children all by caesarean section and breastfed them all for 12 months. The thought of passing this on to my children was too much to bear. I hadn't told anyone about this - not even my partner.

I contacted many services (anonymously) who were all wonderful and supportive. One question they all seemed to ask was how secure was my relationship and told me that many relationships break up over this. I was quite confident my relationship would survive this if it were only me with the virus but what if I'd passed it on to my children.

I decided to have my children tested, against the advice of some. I felt however that I had to deal with this somehow. I couldn't be anymore depressed than I was at that time, anyway and I thought that no matter what the result I would have to find some way to cope.

The wait was torture. I was anxious, couldn't eat or sleep and I found it very difficult to function at work and I still hadn't told my partner. He was aware that something was terribly wrong but I just couldn't bring myself to tell him at that stage.

Finally I got the results, all three were negative. I then felt confident enough to tell my partner and he too tested negative. His question was "are you going to die?" and I said apparently not and he said "then why are you carrying on like such a jerk".

He doesn't have a problem with it at all and is very supportive.

I still have lots of anxieties about hep C so each six months I have liver function tests done and have a PCR test done every 12 months (my choice). I am also very careful about household transmission. I don't allow any blood to blood contact and I only use razors once and throw them away.

I feel quite fortunate in that every single person I spoke to was wonderful. I can't imagine how different things could have been had I have been treated badly as some people are.

To this day I have not disclosed this information to anyone except my husband and doctor and I doubt that I ever will. Although I never thought the day would come I would write a letter to *The Hep C Review* either.

Name supplied

Thanks for sharing your story with us.

As a support organisation, we tend to hear from more people who are doing it tough. Although some of our personal stories reflect quite traumatic hepatitis C experiences, not everybody is affected this way.

Indeed, we hope that people who have not found their HCV experience troubling - or who have overcome their problems and challenges - will also write in with these stories. Like all HCV stories, they are so valuable to share.

Your reference to "every single person I spoke to was wonderful" perhaps highlights the enormous progress that's taken place over the last 5 years and how well developed the support services are here in Australia - as compared to many overseas countries. It also reminds us of the valuable role such services perform within the Australian community and the need for continued (and in many cases, increased) government support.



Worldwide websites

If you want to find out more about hepatitis C - and related topics - why not jump on the net and surf some sites?

It's a great way to spend an hour or two but remember that it may be frustrating not being able to find exactly what you want and you may easily find people's personal opinion and incorrect information dressed up as fact.

Accordingly, other than for our own website <www.hepatitisc.org.au> we can't vouch for the accuracy of information you may find on these listed sites. If you have queries, contact the NSW Hep C Helpline (see page 42).

Medical Images on the Internet

Human Anatomy Online - InnerBody.com:

<http://innerbody.com/htm/body.html>

The Visible Human Project:

www.nlm.nih.gov/research/visible/visible_human.html

<http://research.med.umkc.edu/teams/cml/imagelinks.html>

Three dimensional medical reconstruction:

www.crd.ge.com/esl/cgsp/projects/medical/

eAtlas of Pathology [Liver]:

<http://155.37.5.42/NAV/MSLiver.HTM>

Pharmacological Hepatitis

Drug-induced hepatitis:

www.adam.com/ency/article/000226.htm

Toxic Hepatitis

A Database of Hazardous Chem. and Occup. Diseases:

www.haz-map.com/refernc.htm

Industrial Chemicals Associated with Toxic Hepatitis:

www.haz-map.com/heptox1.htm

Agency For Toxic Substances and Disease Registry (ATSDR):

www.atsdr.cdc.gov/atsdrhome.html

Blood

Blood Tests Explained (HCF):

www.hepcfoundation.org/disi_bloodtest.html

Sterilization or Disinfection of Medical Devices (CDC):

www.cdc.gov/ncidod/hip/sterile/sterilgp.htm

Diseases of the Blood and Blood Forming Organs (UW):

<http://weber.u.washington.edu/~ebm/icd9/blood/index.html>

International Red Cross (ICRC):

www.icrc.org

Australian Red Cross Blood Bank:

www.arcbs.redcross.org.au

Hemophilia Home Page:

<http://merlin.web-depot.com/hemophilia/>

Thalassaemia International Federation (Coole's Anemia):

www.thalassaemia.org.cy/

Thalassaemia Society of Victoria

<http://avoca.vicnet.net.au/ntsvic/>

Sickle Cell Society:

www.sicklecellsociety.org/

Repeated blood cell transfusions...Iron Overload (UT):

<http://medic.med.uth.tmc.edu/ptnt/00001041.htm>

American Hemochromatosis Society:

www.americanhs.org/

Over the next couple of editions we'll provide more listings of interesting websites relating to: nutrition, herbs/Chinese medicine, basic sciences (medicine), genetics & virology.

A Council profile

Introducing Lynne Martin, Project Worker

What's your work background Lynne?

I trained as a nurse, then after a couple of years did some travelling and worked as a nanny, a cleaner and an hotel worker. Then I was a student again for quite a while (having decided to get out of shift work) and worked as a camp nurse in the USA during the summers off.

How did you come to be at the Hepatitis C Council?

After I moved here (from Scotland to Oz), I worked in country NSW for 6 months and applied for every health education job going. I was offered this post just as I was about to give up and go back home.

How is the work so far?

It's a great learning experience, as any job should be. Both professionally and personally I've developed new skills and improved on existing ones. Mostly I take calls on the *Hep C Helpline* but there are lots of other projects involved, such as resource development, training, volunteer support, report writing, statistics collation.

On to the personal stuff Lynne; do you have any hobbies?

Of course. Cooking, visiting friends, reading, movies & theatre, travel, cycling (in nice weather) and bushwalking / outdoors type stuff. Not necessarily in that order and depending on my mood at the time. I also love listening to music as a pick-me-up. And my friends would say talking and I'm inclined to agree with them on that.

Do you have a party piece?

I do a great Scottish accent.

What are you reading at the moment?

A very disturbing Patricia Cornwell novel about Dr. Kay Scarpetta, forensic pathologist!



A favourite food?

Vegetables, preferably Thai or Indian dishes. And I hate avocado, olives and Vegemite!

Anything else to tell us Lynne?

My work here and the friendly bunch I work with really keep me going just now because I miss my close friends and my nieces and nephews at home. And I miss my Gran. But also I have the beach nearby and go for exercise walks a couple of times a week. The sound of the waves is a great relaxer and a reminder that I can't do beach stuff in the homeland without the benefit of a cold weather survival suit.

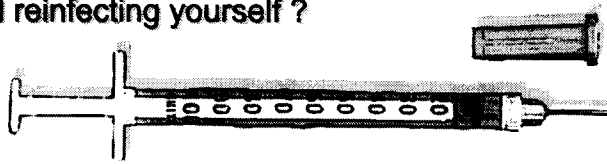
One more thing - any wise thoughts?

Absolutely. No matter how bad things get, don't forget to smell the flowers.

Q: How can you inject yourself without catching Hep C ?

Q: If you have Hep C, how can you avoid reinfecting yourself ?

A: See below.



**Avoid Hepatitis C When Injecting -
Whenever possible, try following this guide to avoid any contact with blood.**

The amount of blood needed to infect someone with the Hep C virus can be so small that you can't even see it.

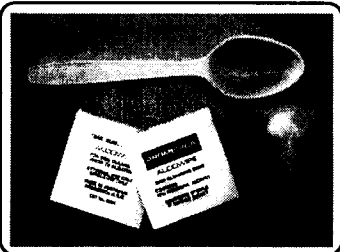
Injecting Gear

Get your own new fit, spoon, water, filter, swab and tourniquet.

Keep it clean

Wash your hands with warm soapy water and clean your spoon with a fresh swab.

Clean the fingers you'll use to pull off a filter with a fresh swab.

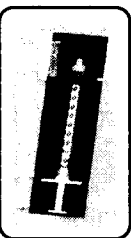


Keep all your injecting gear separate from other people's gear. For example; a shared tourniquet could have been touched with (invisibly) bloody fingers or may rub over someone else's injection site, then over yours, sharing blood and Hep C. Sharing a spoon or water to mix up with is also an easy way to catch Hep C.

Do it Yourself

Inject yourself - if someone else does inject you, make sure they've washed their hands first! And don't forget to **only use your injecting gear.**

While You Inject



If you get blood on your fingers, go and wash your hands before you touch anything on the table - if someone tells you to pass them something, tell them to wait.

If you do touch something by accident, (a cup, fit bin - whatever) let your mates know not to touch it themselves before they hit up.

Wash your hands after touching anything that someone else may have touched.

Remember

Use new equipment every time - Your fit, Your water, Your filter, Your swab, Your tourniquet - **It's Your Life!**

Wash your hands with soap and water.

Make sure the bench or table where you're injecting is as clean as possible.

Can't be bothered with all that shit?

If this all seems too hard, remember that many suggestions are common sense - it's all about avoiding even the smallest amount of blood contact.

A bit of preparation, having new injecting gear on hand and thinking it through is all it takes. For more information on local needle & syringe programs, contact ADIS - 9361 2111 (Sydney) or 1800 422 599 (NSW).

Why should I be bothered about Hep C? Most people I know who hit up have it. Anyway, I use clean fits...

Not everybody gets really crook from hepatitis C (you may know people who are positive and who are fine at the moment). Some people, however, can get really sick.

Most people with Hep C infections in Australia were infected whilst injecting drugs. By the time you've been hitting up for 3 years your chances of having caught Hep C are pushing 50/50. If you keep going for another couple of years it's pretty unlikely that you'll miss out on the virus.

However, even if you already are hepatitis C positive, it's important to avoid getting infected again. **Being Hep C positive doesn't provide you with any protection from getting infected again. Every time you come into contact with the virus it is like you have been infected for the first time, and people with multiple infections of the Hep C virus are often the ones who become sicker.** Multiple infections also have a higher chance of leading to cirrhosis and liver cancer.

No one has to get Hep C from hitting up if they can take a little extra time to think the process through and take care on what they're using and touching when they hit up. Don't just accept that all people who inject have to be hepatitis C positive. It is possible to avoid catching or giving someone hepatitis C when injecting - you just have to change the way you inject. **Just using clean fits isn't enough.**

The key to locking out hepatitis C is to avoid other people's blood. We're not just talking about big pools of the red stuff, which would be easy to avoid, but also the tiny unseen amounts of blood that can get on your hands, on the spoon, on the water ampoule, even on the sides of the disposal bin. A friendly person putting a finger on your vein to stop bleeding can be enough or sharing a swab.

So injecting clean is not just about using a new fit for every hit, but also about using new, clean equipment (water, spoons, filters, swabs) and making sure you or anyone else injecting washes their hands before and after their hit and before touching anything or anyone else.

Don't care about Hep C or your liver but you do care about having fun? Well, read on..

The liver may not seem the body's most exciting organ. Another big blobby piece of meat inside your guts. It doesn't give you any sexual pleasure and you can't use it to suck up drugs with. Why should you care about something that you've never even seen or felt? If your liver is healthy you may never think about it - why should you? Well, if you inject drugs you should pause and think about it. Without your liver working well, injecting drugs can make you feel extra shit-house and the after-effects, well let's hear it from someone who knows:

"Take it from me, being chronically ill isn't fun and it really changes what you can and can't do. While I still think that injecting drugs is great, I've also found that the feeling of sickness, (due to my poor Hep C damaged liver's reaction to injecting) isn't so great. So, after much listening to my sick liver, I've recently decided that it's time to stop hitting up and pursue some less intense interests." (Hep C positive injector)

Mono-therapy

People with significant symptoms, raised ALT levels and chronic persistent hepatitis, and all those with chronic active hepatitis on biopsy, irrespective of symptoms, can be considered for interferon mono-therapy treatment. It involves injections, three times a week, for twelve months. Only around 20% of people, overall, maintain a good long-term response. People who already have cirrhosis don't respond as well to interferon - only around 10% have a good response.

Interferon treatment nearly always involves side effects. Some people report no problems at all while others find the side effects so unpleasant they stop treatment. If considering treatment people should be aware of the possible side effects before making a decision. If concerned, someone may decide to postpone treatment until a particularly demanding work project or other personal commitment is completed.

Interferon side effects can include flu-like symptoms - fevers, chills, lethargy, muscle pain, and depression. Existing depression and mood swings may worsen and need to be monitored closely. Overall, side effects may gradually lessen as a person's body develops a natural tolerance to the drug.

An initial psychological assessment should be given. If someone has a history of psychological problems such as depression, interferon treatment may still be given but will be monitored especially closely as it can worsen such pre-existing conditions. Less common side effects can include mild temporary hair loss, blood disorders, thyroid disorders, skin lesions and worsening of *psoriasis* [a skin disorder]. Overall, most side effects will usually go away once treatment stops.

Mono-therapy eligibility

Interferon is available through the Pharmaceutical Benefits Scheme S100 category for people who meet the criteria listed below. Treatment centres exist in every state and territory. They should offer a nurse educator/counsellor for patients, 24 hour patient access to medical advice, a day-stay liver clinic and facilities to do safe liver biopsies. To access subsidised S100 interferon treatment, people need to meet the following requirements:

- ⊙ have a liver biopsy that shows chronic hepatitis (waived for people with clotting disorders)
- ⊙ have a repeatedly positive HCV positive test
- ⊙ have raised ALT levels in conjunction with demonstration of viral infection (HCV antibody positive and/or HCV PCR positive)
- ⊙ do not have cirrhosis or other liver disease
- ⊙ are not pregnant or likely to become pregnant during treatment
- ⊙ have no history of major psychological problems - eg. schizophrenia, major depression
- ⊙ be able to attend regularly for treatment and follow up
- ⊙ drink no more than seven standard drinks per week

Combination therapy

Government subsidised S100 combination therapy is available only to people who have previously had interferon monotherapy (where such treatment would have complied with S100 criteria for PBS subsidy) but relapsed. It consists of interferon and ribavirin, collectively manufactured under the name "Rebetron". It involves a 6 month course of interferon injections (3 times a week) and ribavirin capsules (taken twice a day). People are asked to visit their GP or specialist for follow up visits during and after treatment. S100 subsidised combination therapy is withdrawn after three months of treatment if HCV RNA still remains detectable (ie. if a person remains PCR positive).

Studies have shown that people with hepatitis C are more likely to have a sustained response with combination therapy than with interferon alone. Overall, a person's chance of responding well to combination therapy is related to their hepatitis C genotype and the amount of virus in their blood. To date, genotypes 2 and 3 have been shown to have a higher response rate (60-70%) to combination therapy than genotypes 1 or 4 (20-30%). If people have responded to previous interferon monotherapy but then relapsed, there is still a good chance of response with combination therapy. Those who did not respond to previous interferon have only a low chance of responding to the combination therapy.

Many people who have considered the relative response rates and are interested in combination therapy are holding off interferon monotherapy while awaiting a possible change to S100 guidelines that may allow for combination therapy as a first option for hepatitis C treatment.

Side effects with combination therapy vary for each person and do appear to become less severe as treatment continues. They are similar to those experienced with interferon alone (see left). A potentially serious side effect of ribavirin is anaemia. People's blood counts are monitored very closely, especially in the first few weeks, and doctors may reduce the ribavirin dose if necessary. Ribavirin has also been shown to cause birth defects and combination therapy is not available to women who are pregnant or breastfeeding, or to anyone (women and men) not using adequate contraception during treatment or up to six months afterwards. Treatment centres will be able to provide detailed information about possible side effects and how to manage them.

NSW treatment centres:

Greater Sydney

Bankstown-Lidcombe	Blacktown
Campbelltown	Concord
Corrections Health (Long Bay)	Liverpool
Mount Druitt	Nepean
Prince of Wales	Royal North Shore
Royal Prince Alfred	St George
St Vincent's	Sutherland
Westmead	

Regional NSW

Bathurst	Bega
Coffs Harbour (Base)	Corrections Health (Bathurst)
Dubbo (Base)	Illawarra
John Hunter	Lismore (Base)
Orange (Base)	Port Macquarie (Base)
Wagga Wagga (Base)	Wodonga (Albury)

Complementary therapies

Complementary or alternative 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, homoeopathy, herbs or other methods aim to improve the overall health of their patients.

Good results have been reported by some people using complementary 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 complementary 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 complementary or 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 reasonable 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 complementary 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 complementary 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, you may want to consider changing your natural therapist.

Researched?

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 previous Australian trial of one particular Chinese herbal preparation has shown some positive benefits and few side-effects (see Ed 15, p6). A similar trial but on a larger scale has been initiated in the NSW Northern Rivers region (see Ed 24, p8).

Want more information?

For general information about complementary therapies, phone the NSW Hep C Helpline (see page 42).

Additionally, contact any of the following organisations:

Association of Remedial Masseurs	9807 4769
Australian Acupuncture Association	1800 025 334
Australian College of Acupuncturists	4677 2358
Australian Homoeopathic Association	9713 2793
Australian Natural Therapists Association	1800 817 577
Australian Traditional Chinese Medicine Assoc.	9699 1090
Australian Traditional Medicine Society	9809 6800
Homoeopathic Association of NSW	9247 8500
National Herbalists Association of Australia	9211 6437
NSW Association of Chinese Medicine	9212 2498
Register of Traditional Chinese Medicine	9660 7708

Hep C Helpline

For free, confidential and non-judgemental information and emotional support you can phone the NSW Hep C Helpline:

9332 1599 (Greater Sydney callers)

1800 803 990 (NSW regional 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.

Community health 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.

Look in your White Pages under 'Community Health Centres'. Neighbourhood Centres can be found by phoning your local town Council.

Sexual health clinics

Although hepatitis C is not classified as a sexually transmissible 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 or Medicare card and keep all medical records private.

Alcohol & other drug services

NSW health services have a number of Drug and Alcohol clinics set up around the state. These centres offer confidential advice, assessment, treatment and referral for people who have a drug/alcohol problem or who have concerns about the use of these substances.

The services are free and the staff are experienced in all aspects of drug and alcohol use and the associated conditions that go with them. If you are worried about your own or someone else's drug and alcohol problem, phone the Alcohol & Drug Information Service (ADIS) on 9361 2111 or 1800 422 599, or contact your local hospital or community health centre who will also be able to advise you on your nearest clinic.

Your local hepatitis C services contact

Greater Sydney

Central Sydney	Peter Todaro	9515 3375
Nthn Sydney	Graham Stone	9926 6717
SE Sydney	Lesley Painter	9382 8370
Sth West Sydney	James Mabbutt	9828 5944
Wentworth area	Elizabeth O'Neill	4724 3877
Western Sydney	Chris O'Reilly	9840 4105

Regional NSW

Central Coast	Judy Hewitt	4320 3399
Far West NSW	Darriea Turley	08 8080 1511
Hunter	Marilyn Bliss	4924 6477
Illawarra	Brian O'Neill	4228 8033
Mid Nth Coast	Robert Baldwin	6588 2789
Mid West NSW	Dave Brackenreg	6339 5576
New England	Karin Ficher	6766 2288
Nthn Rivers	Kerry Leitch	6620 7505
South West NSW	Dalton Dupuy	6058 1700
Southern NSW	Geetha Isaac-Toua	4827 3428
Western NSW	Scott Davis	6885 1700

Other support & counselling

TRAIDS is a statewide counselling, support and advocacy service for people with medically acquired hepatitis C and HIV. They offer short and long-term counselling, information, support and advocacy to affected people and their families and/or carers. TRAIDS services are free and confidential, and on either a face-to-face or telephone basis. They also run support groups and have a regular newsletter. Current hepatitis C information is available. For more information, contact Yvonne or Sheelagh on 02 9843 3143 (for NSW regional callers, TRAIDS have an immediate call back policy).

Family & relationship counselling

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

To find out more, contact *Relationships Australia* (ex-Marriage Guidance Association NSW) on 9418 8800 or 1800 801 578.



"The Hep C Review is going to jail"

Thank you to everyone who was able to return their survey on *The Hep C Review* and prisons.

By posting these back to us, you are helping in the development of information and support resources that meet the needs of all people in NSW.

Just a reminder also that there is no definite closing date for the survey. If you still have your survey form, to ensure you have your say in the project, please don't hesitate to post it back.

Do you have a hep C story to tell?



If so, we'd all love to hear it.

Your story can be kept confidential and does not need to carry your name, suburb, etc.

So please send in your stories to us. They are such an important feature of our magazine.

Also, the Council is always looking for people willing to do media work and can offer training.

Call us on 9332 1853 if you are interested.

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

Videos are borrowed for two weeks at a time and will only 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.

Eds 1-18 available on request

Ed 19 - notifications / diagnosis / understanding research

Ed 20 - PCR / biopsy / treatments / transplant / tattooing

Ed 21 - legal issues / liver function tests / sexual transmission

Ed 22 - living with chronic illness / painkillers & HCV / alcohol & HCV

Ed 23 - The Neglected Epidemic / overseas update / genotypes

Ed 24 - alternative therapies / fatigue / Pegasys interferon trial

Ed 25 - current & evolving drug treatments / interferon side effects

Ed 26 - living better / combo therapy / 2nd Australasian conference

Ed 27 - seeking support / HCV & disclosure / summarising Aust. response

Ed 28 - decline in HCV prevalence / dry mouth & dental care

Hepatitis C - a brief introduction - (brochure)

Hepatitis C - what you need to know - (booklet, single copies free)

Hep C Helpline - Poster and calling card (bulk copies available free)

"Hepatitis C: understanding is the answer" campaign posters (free)

Video 1 - *Interferon / HCV & women* - (you pay return postage)

Video 2 - *homoeopathy / herbalism* - (you pay return postage)

Video 4 - *hepatitis C / the liver* - (you pay return postage)

Look Back Look Forward - video (you pay return postage)

Research Pack 1 - epidemiology / prevention / serology / diagnosis

Research Pack 2 - overview / National Action Plan

Research Pack 3 - 1994 NHMRC Hepatitis C Report

Research Pack 4 - surveillance / post-transfusion HCV / herbalism

Research Pack 5 - AHMAC / NSW Taskforce Report

Research Pack 6 - prisons / treatment / IDU / PCR

