

# *The Hep C Review*

Autumn Issue March 2005

Edition 48

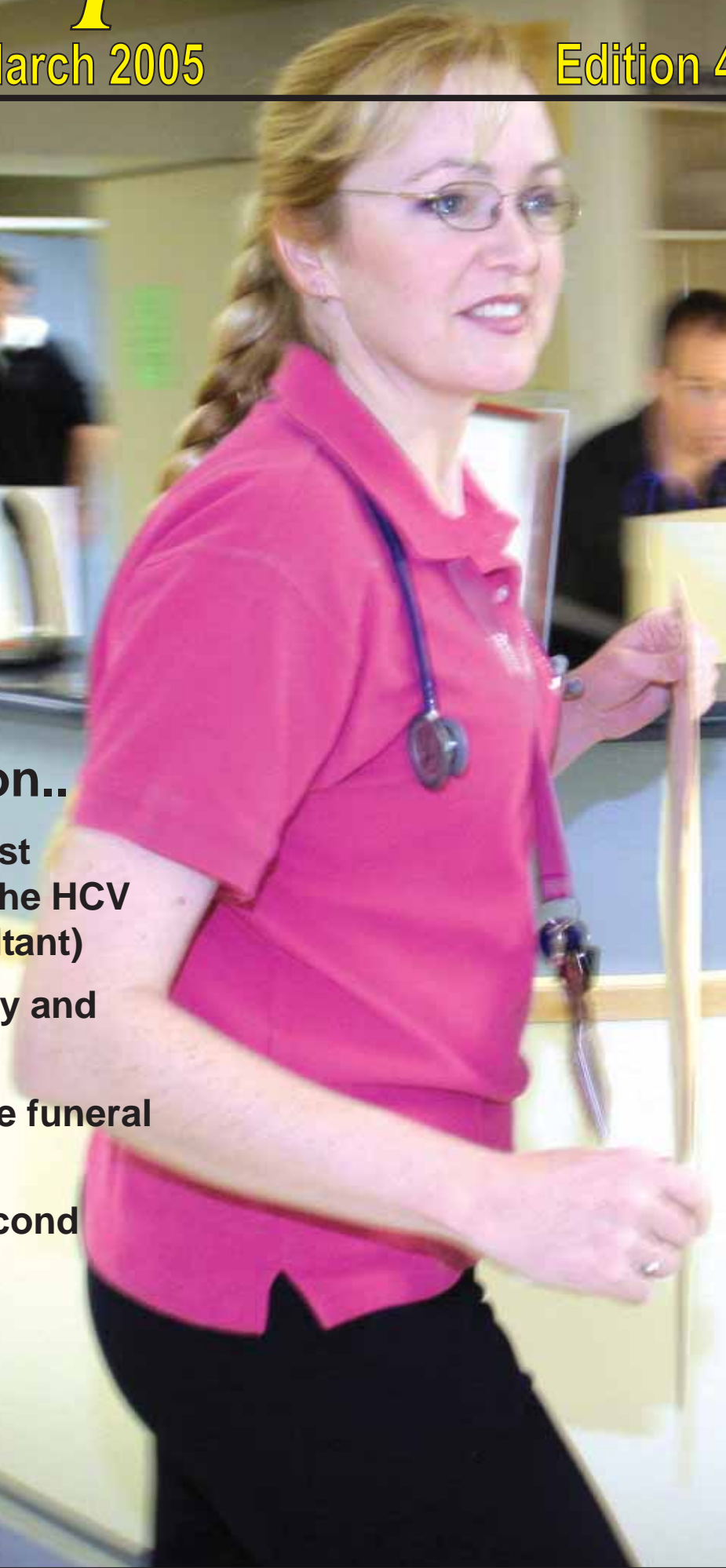
## **Inside this edition..**

**Looking after your best interests (the role of the HCV Clinical Nurse Consultant)**

**Hepatitis C, pregnancy and child raising**

**New guidelines for the funeral industry**

**Opinion - Prison's second sentence**



## editor's intro

Here at the Council we wish a warm 2005 welcome to all our readers. We hope you have weathered the Christmas season festivities and are sticking to any resolutions you may have made.

In this edition of *The Hep C Review* we present our usual mix of letters, news, opinion, information articles, personal stories and research updates.

To help place Australia's hep C epidemic in an international context we continue to obtain as many news items from overseas as possible. In addition to the local news we hope these articles help to keep you up-to-date on developments in knowledge and treatment of HCV.

One news item in this issue concerns the *Hepatitis C Choices* website. If you have internet access, consider visiting this site. It is a truly valuable source of hepatitis C information... <http://www.hepcchallenge.org/>

Speaking of hepatitis C information, we must pay tribute to our friends at the US-based *Hepatitis C Support Project*. You will note in this edition our continued reliance on their excellent website as a source for information... <http://www.hcvadvocate.org/>

HCV Advocate writer Lucinda Porter has contributed an article to this issue titled, Herbs and Hepatitis C (pg 24). Although written for an American readership, we hope this piece provides insight into the use of complementary therapies for dealing with hepatitis C.



Complementary therapies were shown to be the most popular topic in our most recent readership survey. If you would like to comment on our coverage of complementary therapies, please don't hesitate to write in. We'd be very keen to hear about what you'd like to see covered.

Other interesting features in this edition include the article by Prof Bob Batey and Tracey Jones titled, *Hepatitis C, Pregnancy and Child Rearing* (pg 12). Reading it I am reminded of some of the issues I encountered as the HCV positive father of a young daughter (she was aged three when I received my diagnosis).

Our article on the funeral industry (pg 14) marks a high point in an ongoing campaign to address unacceptable practices in that industry. It details welcome amendments to guidelines that will ensure that people, recently bereaved, do not suffer from the ignorance of funeral workers.

A timely article, *Looking after your best interests* (pg 20), describes the role of HCV Clinical Nurse Consultants. Working at a large metropolitan hospital, these staff are a key cog within the overall treatment program. They play an essential role in overall coordination, education and support. If, like me, you are considering combination treatment, you'll be one step ahead with the help and involvement of your treatment centre's HCV CNCs.

Here at the Council, one could be mistaken for thinking that things would be comparatively quiet. We have two staff off on holiday - Stuart Loveday overseas on holiday and long service leave, and myself off for a months' leave, sailing down to Tassie and back.

Stuart's ten year long service rewards are well earned. He has guided the Council over a decade of hepatitis C developments and we are indebted for his thoroughness and commitment to the hepatitis C communities.

With two staff away, this is not to say that the atmosphere at the office is dull. Our new staff member, Holly Beasley, is settling in to her role as our Project Officer - Education & Development. Grant Malpas, our recently appointed Coordinator - *Hep C Helpline* (pg 39) is hard at it, giving the *Helpline* room a refreshing renovation and make-over.

The next time I sit writing an introduction, the trees outside (see left) will have lost their leaves and winter will be upon us. I hope your guardian angel watches over you and Edition 49 finds you fit and well.

Within Edition 49 we will carry news of the upcoming National Hepatitis C Treatments Awareness Week (see pg 37).

Until then,  
best regards,  
**Paul Harvey**  
Editor

## Calling all members

Thank you so much for your ongoing support for our Council.

Our 2005 membership year began on 1 March and renewals are now due.

New applications for membership are always welcome.

Please refer to the loose-leaf flyer and membership form enclosed for your convenience.

The Hepatitis C Council of NSW is an independent, community-based, non-profit, membership organisation. We are funded by the NSW Health Department.

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Contributions to *The Hep C Review* are welcomed and are subject to editing for spacing and clarity. Contributors should supply their contact details - although we do not publish such details unless asked to.

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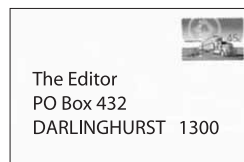
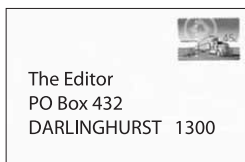
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## Paying the piper?

A senior staff member of United Nations Office on Drugs and Crime (UNODC) sent the following email to more junior staff in November 2004.

"UNODC policy on needle exchange is reflected in the statement of [our] Executive Director. Nevertheless, and again taking our guidance from the [UN] conventions, the Commission on Narcotic Drugs and the International Narcotics Control Board, we neither endorse needle exchange as a solution for drug abuse, nor support public statements advocating such practices"

"The Project & Program Committee ... requested changes to the language of some projects to eliminate references to harm reduction and needle/syringe exchange. Please ensure that this policy is observed in our projects and programs. Please also ensure that references to harm reduction and needle/syringe exchange are avoided in UNODC documents, publications and statements."

It is understood that this email followed discussion between senior UNODC and senior members of the US government following the re-election of George W Bush on 2 November. These discussions are also understood to have included the possibility of the US government withdrawing funding from UNODC if the desired changes did not take place.

This email raises many questions. HIV/AIDS is the greatest global health problem since the Black Plague of the 1340s. It is getting worse. By 2010, the epicentre will shift from Africa, where injecting is a small problem, to Asia - home to half the world's population and a region where drug injecting is the major or second major route of transmission in most countries.

The evidence that harm reduction, in the form of methadone maintenance treatment and needle syringe programmes, reduces HIV infection substantially is now incontrovertible.

It is of course the right of the US government to be less than luke warm about methadone maintenance treatment and needle syringe programmes even though the US has the highest proportion of AIDS cases attributed to injecting drug use in a developed country. But exporting this folly to international organisations ensures that HIV/AIDS will be an even bigger problem in the future.

UNODC is part of the UNAIDS consortium and should stand up to threats from member governments - including the US - if these threaten to imperil HIV control.

It is vital that pragmatic, effective, evidence based responses to the threat of HIV spreading among IDUs are established and expanded quickly and soon reach a scale commensurate with the problem.

**Alex Wodak**

## Hepatitis C can be stopped by good quality maintenance treatment

At last there is some good news about hepatitis C. In an article published recently the *ANZ Journal of Public Health*<sup>\*</sup>, we have shown that the incidence of HCV can be kept very low in drug users who are in treatment (with methadone or buprenorphine).

While much of the recent information about this virus shows continued sero-conversions as being the rule, this study shows that by using treatment consistent with established guidelines, such cases can become exceptional. In fact, it was our experience that nearly all of the few cases of sero-conversion were in patients who had their treatment interrupted and/or had been placed in custody for a time.

Between January 1996 and July 2003, 54 treatment entrants were initially HCV negative. In the study period five sero-conversions occurred. Four sero-conversions occurred in the sub-group with interrupted opioid replacement therapy (n=20). One sero-conversion occurred in the sub-group with continuous opioid replacement therapy (n=34).

The authors conclude: "HCV incidence among IDUs receiving opioid replacement therapy in our clinic was relatively low. Those IDUs without interruptions to their treatment appeared to be at particularly low risk of HCV infection. These findings support the role of opioid replacement therapy in HCV prevention for IDUs."

**Andrew Byrne.**

\* Hallinan R, Byrne A, Amin J, Dore GJ. Hepatitis C virus incidence among injecting drug users on opioid replacement therapy. *ANZ Journal Public Health* (2004) 28;6:576-578

## NSW government rules out gaol needle programs

*Australia* - The New South Wales government has rejected as "ridiculous" a proposal to set up needle exchanges in the states' correctional centres.

The proposals were made in "Supply, Demand and Harm Reduction Strategies in Australian Prisons: Implementation, Cost and Evaluation," a report published today by the Australian National Council on Drugs.

Justice Minister John Hatzistergos said, "Drugs are illegal in correctional centres and we devote a huge amount of time, effort and resources to keep them out."

He said the government already has rehabilitation and counselling services for the 70-80 percent of inmates who had drug problems before entering the correctional system. "But we will not countenance handing out needles to inmates to assist them with illegal activity inside our jails," the minister said.

"Why on earth would we consider undermining our zero-tolerance policy on drugs by allowing a needle exchange?"

The minister said, "The needle-exchange proposition is ridiculous and is an unacceptable safety risk to staff."

Despite opposing needle-exchange programs in prisons, Hatzistergos said the government acknowledges the need for them in the community.

> Abridged with thanks from an AAP news item, 16 Nov 2004. (Also see pgs 19 & 42.)

## Breath test your liver

*Australia* - Researchers have developed a breath test which could replace painful liver biopsies to detect liver fibrosis and cirrhosis in people with liver diseases including hepatitis C.

The breath test, which is still under evaluation, involves a drink which has been 'tagged' with a special carbon molecule. After one hour, the breath test can measure the amount of tagged carbon molecules in expired breath, giving doctors a measure of liver damage.

> Abridged with thanks from an AAP news item from *Positive Living*, Oct/Nov 2004.

## Syringe program pays off

*Australia* - St George Hospital's Needle and Syringe Program (NSP) has contributed to a reduction in the transmission of HIV, hepatitis and other diseases in South East Sydney Health's area, a report has found.

Director of sexual health Christopher Carmody said many people believed a program focused on stopping illicit drug use should be implemented but the reality was that some people would inject drugs regardless of the risks.

"Many studies have shown that harm-reduction services such as NSP do not contribute to the uptake of illicit drug use, nor do they increase the level of drug use among people who inject drugs," Dr Carmody said.

"Initiation into drug use is complex and influenced by cultural, familial, psychological and historical factors."

If you are in NSW and find a discarded syringe, phone the Needle Cleanup Hotline on 1800 NEEDLE (1800 633 353).

> Abridged with thanks from *The Leader*, 14 Dec 2004.

## Mouse to help fight hepatitis C

*India* - A genetically engineered mouse will soon be used in a new initiative by Indian and German scientists to prevent hepatitis and other communicable diseases.

Under an agreement to be signed in March by the German Research Centre for Biotechnology (GBF) and the Indian Council of Medical Research, scientists will develop a mouse that would be infected with the hepatitis-C virus, said Rudi Balling, GBF's director.

"So far, it has been impossible to create a study model for the disease. But we are trying our best since a mouse in many cases behaves like humans," Balling told IANS on the sidelines of the Indian Science Congress here.

The mouse would receive human immune cells derived from the umbilical cord of a foetus and be infected with the "hepatocides" that cause the Hepatitis-C disease.

"It would help in our study to a great extent," said Balling, whose organisation does a lot of work with "mouse genetics".

> This Indo-Asian News Service item was abridged with thanks from [www.hcvadvocate.org](http://www.hcvadvocate.org)

## New York votes to reduce harsh sentences for minor drug offences

USA - After years of false starts, state lawmakers have voted to reduce the steep mandatory prison sentences given to people convicted of drug crimes in New York State, sanctions considered among the most severe in the nation.

The push to soften the so-called Rockefeller drug laws came after a nearly decade-long campaign to ease the drug penalties instituted in the 1970's that put some low-level first-time drug offenders behind bars for sentences ranging from 15 years to life.

While some elected officials and drug policy advocates hailed the drug sentencing changes as a major step forward, others complained that they did not go far enough. They complained that inmates serving what they called unduly long prison terms for lesser crimes would not be allowed to apply for early release, and that judges were not given the power to sentence some offenders to treatment programs rather than prison.

A study by the Democrats in the State Senate found that New York State imposed the harshest penalties in the nation for low-level drug offenders. It found that 32 states, including Texas and Florida, offer probation to non-violent offenders who sell small amounts of drugs, and that New York was the only state that required more than three years in prison for such offences.

› Abridged with thanks from a *New York Times* article, 8 Dec 2004, circulated via ADCA Update.

## Mbeki blood rejected

Blood donated by the South African president, Thabo Mbeki after an urgent appeal for donors was destroyed because it was regarded as a health risk.

The country's National Blood Service incinerated the President's donation after he failed to complete a compulsory questionnaire about his personal health, a spokesperson said on Sunday. - *The Telegraph*, London.

› Reprinted with thanks from the *Sydney Morning Herald*, 7 Dec 2004.

## Hep C at epidemic levels among young injectors in London

Levels of hepatitis C among young injecting drug users across London are reaching epidemic levels, report researchers from Imperial College London, the Health Protection Agency and the London School of Hygiene and Tropical Medicine.

According to the study, published in the *British Medical Journal*, four in ten new young injectors now has hepatitis C, while three per cent are now infected with HIV.

Hepatitis C, which can cause serious and sometimes fatal liver damage, is mainly spread by sharing needles and syringes. Preventing HCV transmission among injecting drug users is critical to avoiding significant later health consequences in the population and associated treatment costs.

Dr Ali Judd, from Imperial College London, based at Charing Cross Hospital, and one of the authors of the study, comments: "Hepatitis C is now spreading at epidemic levels across London and HIV incidence is worryingly high, which if unchecked will lead to an increase in the total number of HIV infections. There is an urgent need for new and comprehensive programmes to tackle this growing problem."

The study was made possible through the use of saliva and blood spot tests for HCV and HIV developed at the Health Protection Agency Centre for Infections. Of those that were HCV negative or HIV negative at the first interview they found 42 per cent and 3.4 per cent were infected with HCV and HIV respectively one year later. The researchers also found high levels of syringe sharing, with one in four reporting injecting with needles and syringes that had been used by someone else in the last four weeks and one in two sharing other injecting paraphernalia.

The researchers believe a number of factors may have contributed to the rise in the incidence of HCV and HIV. These include a rise in the number of injectors, without any increase in the number of syringes distributed through syringe programmes, more risky injecting behaviour in newer injecting drug users, and greater levels of crack injection. There has also been a lack of targeted health promotion campaigns about hepatitis C in recent years.

› Abridged with thanks from [www.hcvadvocate.com](http://www.hcvadvocate.com)

## US health officials probe hepatitis C cases

*USA* - A vial of a radioactive solution, 12 hepatitis C cases and one death so far are the elements of a mystery that has left health officials pondering.

The cases were from a group of 16 people injected with the solution for routine heart-stress testing, all from a single vial produced by a Timonium pharmacy run by Cardinal Health.

Among them was John Leto, 80, a Brooklyn Park man who died of pneumonia on Christmas Day after suffering from hepatitis C, a disease of the liver.

Investigators are now trying to learn how the 12 were infected, a probe that could take months to complete, said John Hammond, a spokesman for the state health department.

Cardinal Health said the investigation is focusing on the way the doses were prepared and not on the pharmaceutical tracer contained in the doses.

The US Centres for Disease Control said recent studies have found the hepatitis C virus can survive on surfaces at room temperature for at least 16 hours, but no longer than four days. Medical and dental procedures in the United States generally do not pose a risk for spreading hepatitis C, but it has occurred in a few situations when supplies or equipment were shared, according to the CDC web site.

> This <http://wjz.com> article was abridged with thanks from [www.hcvadvocate.com](http://www.hcvadvocate.com)

## Irish gaol reform trust slams mandatory drug tests

*Ireland* - The Irish Penal Reform Trust has criticised Justice Minister Michael McDowell's plans to introduce mandatory drug testing in all Irish gaols.

The trust said today that the plan would have no impact on drug abuse among inmates and could even make the problem worse.

It said a comprehensive drug treatment program to help reduce the spread of HIV and Hepatitis C in gaols would be a better use of resources.

IPRT director Rick Lines said evidence from other countries showed that mandatory testing was ineffective and counterproductive.

"It has, in fact, had an influence in encouraging people to switch their drug of choice and their method of drug use from smoking cannabis to injecting heroin," he said.

"This is specifically because injecting heroin is less easily detected by drug-screening kits. As a result, you have a situation where you're increasing the risk of transmission of HIV and Hepatitis C in gaols while not making a significant dent in the overall levels of drug use."

> This *Ireland Online* article was abridged with thanks from [www.hcvadvocate.org](http://www.hcvadvocate.org)

## Police station prisoners to be handed free needles

*Scotland* - Prisoners are to be given free needles by police after it emerged that two-thirds of drug users taken into custody in the city are infected with hepatitis C or HIV.

The new scheme is intended to decrease the risk of police officers being jabbed by hidden syringes while searching suspected criminals.

Lothian and Borders Police Deputy Chief Constable Malcolm Dickson today predicted the move would reduce the chances of officers becoming infected with such diseases.

"We are not condoning or encouraging drug use, but we cannot be ignorant about the fact that people are going to take drugs, whether or not we tell them not to," he said.

"A programme like this is about reducing the potential harm to both the police and to the user."

All prisoners are routinely searched before being placed in one of 40 holding cells at St Leonard's police station - where people arrested in Edinburgh are generally held overnight.

Research has shown that about two-thirds of the 6,000 prisoners who use drugs who pass through the station's cells every year are infected with the hepatitis C virus. Many also have HIV.

Needle injuries to police personnel are not uncommon and individuals face an anxious wait of several months before they can be given confirmatory blood tests.

> Abridged from *The Scotsman*, 14 Jan 2005

## Researcher cites bias in head-to-head trial

USA - A lead researcher for a high-stakes trial comparing the world's top-selling drugs for hepatitis C said the study's design could "bias" results in favour of Schering-Plough's product.

"Unfortunately life is not perfect and this study is not perfect as well," Dr. John McHutchison, co-lead investigator of the Schering-Plough trial, told Reuters in an interview on Thursday.

McHutchison, a Duke University researcher, said the study design will probably allow more patients receiving Peg-Intron to stay on stronger doses of ribavirin than those taking Pegasys.

"Maintaining the highest tolerable dose of ribavirin, regardless of which interferon is used, is very important for controlling the virus, particularly in the early part of treatment," he said.

Peg-Intron patients who develop anaemia or other side effects from ribavirin will have their daily dose of the pill reduced by 200 milligrams, with subsequent 200-milligram cuts if necessary. By contrast, Pegasys patients with side effects must have their ribavirin cut back to 600 milligrams in one fell swoop.

"The dose reductions for ribavirin are not equivalent in the two arms of the study and could therefore introduce a potential bias" in favour of the Peg-Intron arm of the trial, McHutchison said.

The FDA insisted that instructions on the Pegasys drug label be followed — any ribavirin reductions must be to 600 milligrams.

> This Reuters article abridged from [www.hcvadvocate.org](http://www.hcvadvocate.org)

## Hepatitis C Choices: third edition released

USA - The Hepatitis C Caring Ambassadors Program (HCCAP) announced the internet release of the newly updated 3rd edition of *Hepatitis C Choices: Distinctive Viewpoints on Choices for Your Hepatitis C Journey*. The book is authored by a team of 20 leading medical experts and community advocates. 'Choices' presents an objective review of conventional and alternative treatment options for people with hepatitis C.

The book thoroughly reviews conventional (western) treatment along with naturopathic, Ayurvedic, homeopathic, and traditional Chinese medicine management approaches. Other important topics such as disease progression, nutrition, laboratory testing, and health care consumer information are also included. In addition to extensive updates, 'Choices' has two new chapters on integrative medicine and immunology.

According to Dr Robert Gish of the Liver Transplant Program at California Pacific Medical Centre in San Francisco, "Hepatitis C Choices provides not only choices on treatment for hepatitis C, it delivers a detailed overview of background information for patients seeking answers to key facts on why their specific treatment pathway is correct for them."

The Hepatitis C Caring Ambassadors Program is a US nonprofit organisation dedicated to increasing awareness about the hepatitis C epidemic and improving the lives of those afflicted with the disease.

> This Reuters article abridged from [www.hcvadvocate.org](http://www.hcvadvocate.org)

'Choices' is downloadable from [www.hepcchallenge.org](http://www.hepcchallenge.org)

## Low-dose therapy slows hep C

USA - For the first time, a study confirms what many doctors thought was true: The progression of hepatitis C can be prevented or delayed by using pegylated interferon as long-term maintenance therapy in patients who have not responded to full-dose interferon therapy.

The study, led by Dr. Nezam Afdhal of the Beth Israel Deaconess Medical Centre, includes 550 people with advanced fibrosis who have previously failed interferon therapy.

"It's a totally different approach" from trying to eradicate the virus with full-dose interferon, Dr. Afdhal said in an interview. In patients for whom interferon does not eradicate the virus, many die of complications from the disease, he said.

"Why not try to lower the dose to prevent complications" and see what would happen, he said he thought before beginning the study.

Patients experience much fewer complications on about one-third the regular dose, he said. Since many patients on interferon fail to complete therapy due to side-effects, this is an important outcome.

> This [www.medicalpost.com](http://www.medicalpost.com) article abridged from [www.hcvadvocate.org](http://www.hcvadvocate.org)

## Caffeine reduces risk of raised LFT results

*USA* - In a large study including persons at high risk for liver injury, consumption of coffee and especially caffeine has been found to be associated with lower risk of elevated alanine aminotransferase activity.

Dr Ruhl and colleagues from Maryland in America designed a study to investigate whether drinking caffeine reduced the risk of elevated alanine aminotransferase (ALT) activity in persons at high risk for liver injury.

In this national, population-based study - reported in *Gastroenterology* 2005: 128 (1) - the researchers recruited a total of 5944 adult participants from a recent US National Health and Nutrition Examination Survey.

The participants exhibited excessive alcohol consumption, viral hepatitis, iron overload, overweight, or impaired glucose metabolism. The researchers found elevated ALT activity in 8.7% of this high-risk population.

In unadjusted analysis, the research team noted that lower ALT activity was associated with increasing consumption of coffee and caffeine.

Dr Ruhl concluded, "In this large, national, population-based study, among persons at high risk for liver injury, consumption of coffee and especially caffeine was associated with lower risk of elevated ALT activity."

> This [www.gastrohep.com](http://www.gastrohep.com) article was abridged with thanks from [www.hcvadvocate.org](http://www.hcvadvocate.org)

## Staff arrivals

Holly Beasley has been appointed to the position of Project Officer - Education & Development, within the Council's Education & Development Team.

Holly comes to us from Perth where she was working for Avon Youth Services as an alcohol and drug youth officer.

Holly's main priorities will be representing the Council on the numerous localised committees, maintaining the secretariat function for *HepLink* - the key network of NSW HCV workers and agencies.

She will also be coordinating the NSW arm of the upcoming National Hepatitis C Treatment Awareness Week Campaign.

> HCCNSW

## Irish health minister apologises formally on hepatitis C case

*Ireland* - The Deputy Prime Minister and Minister for Health, Mary Harney, has formally apologised to a 24-year-old man who contracted hepatitis C from his mother at birth.

The apology was issued after a settlement was reached in a High Court case taken against her and the Blood Transfusion Service Board. The terms of the settlement are confidential, but they are believed to involve a payment of around 2 million Irish pounds.

The man sued the Minister for Health and the BTSB for the pain and suffering caused by contracting the disease from his mother who had been given an infected blood product in 1977. He was 13 when he was diagnosed positive.

> This news article from [www.rte.ie/news](http://www.rte.ie/news) was downloaded with thanks from [www.hcvadvocate.org](http://www.hcvadvocate.org)





# Hepatitis C, pregnancy

**Many misconceptions do exist in relation to hepatitis C and pregnancy and in this article we will seek to make discussion of this issue and decision making around these issues more reasonable and hope**

By Robert Batey and Tracey Jones

Hepatitis C affects many aspects of life and there is no question that there is a very significant interaction between hepatitis C and a woman who is considering pregnancy and child bearing and raising.

Any severe liver disease makes pregnancy more difficult to achieve but as most people with hepatitis C have mild disease and are often these days diagnosed early in the course of their illness it is not unusual for women to fall pregnant whilst having a hepatitis C infection. The first point to stress is that hepatitis C itself does not have any apparent adverse effects on a pregnancy or on foetal development.

It is possible that a pregnant woman may contract hepatitis C whilst pregnant and if she were to experience a severe bout of hepatitis there is an increased risk of foetal loss but, as we know, acute, severe illness from hepatitis C is most unusual and we are not aware of any cases of foetal loss resulting from an acute hepatitis C infection in early or late pregnancy.

The key issues that really require clarification are:

- the risk to the baby of infection with hepatitis C virus,
- the advisability of treatment for hepatitis C pre pregnancy, during pregnancy or after pregnancy and
- the risks to a pregnant mother of a partner undergoing hepatitis C treatment.

## **The risk of transmission of HCV from mother to baby**

Hepatitis C can be transmitted from mother to baby and whilst the exact time of transmission is unclear it is still felt by most authorities that transmission occurs at or around the time of delivery. Hepatitis C is only transmitted to the baby if the mother is positive to hepatitis C RNA (genetic material) at the time of delivery.

Hepatitis C antibody positive mothers who are RNA negative pose no risk to the baby at the time of delivery although the baby will have maternal hepatitis C antibodies circulating for up to 14 months following delivery even if the mother is RNA negative. This simply reflects the normal situation of maternal antibodies crossing to the foetus to protect the baby against a variety of infections in the peri partum period.

The risk of transmission from a hep C RNA positive mother to a baby when all precautions are taken is approximately 6 – 8%. Managing obstetricians and midwives need to minimise any trauma to the skin of the foetus so that the chance of transmission through broken skin is minimised. Whilst a few recent papers suggest that caesarean section may reduce the risk of HCV transmission, those studies have not been large enough to recommend that Caesarean section be done as a routine in HCV RNA positive mothers. This may change in time. In Australia at the moment it would be standard practice to recommend vaginal delivery, with staff taking precautions to avoid blood exposure of the newborn child.

Babies who are born to hep C RNA positive mothers can be tested for hepatitis C RNA and the timing of that is best left for 3 months because of the occasional baby having a transient hep C RNA viremia immediately after delivery. Measuring hepatitis C antibodies will not answer the question as to whether the baby has been infected as the presence of maternal antibodies in uninfected babies is a reality for up to 18 months.

Recommended testing policy would be a hep C RNA on the baby at 3 months or 6 months if one is concerned about identifying transmission early in the baby's life. Treatment is not available to babies or children under the age of 18 unless there is very clear evidence of severe progressive liver problems.

One area that causes hep C positive mothers a great deal of concern is whether to breastfeed or not. Are they putting their child at more risk? Studies have shown that while indicators of the virus have been found in breast milk and colostrum, scientists believe that the virus is inactivated in the gut of the child. They do not believe that it can be transmitted through colostrum or breast milk. The main risk factor to consider is if the breasts are cracked or blood is present for any reason.

## **Hepatitis C treatment and pregnancy**

Should a pregnant woman be treated for hepatitis C? It is abundantly clear that the toxicity of ribavirin to developing foetuses renders it an inappropriate drug for use in pregnancy. Mothers who are hep C positive should be advised that their risk of transmission to family and to the foetus is low and that the pregnancy will progress safely so treatment should not be used in the pregnancy at all.

# and child raising

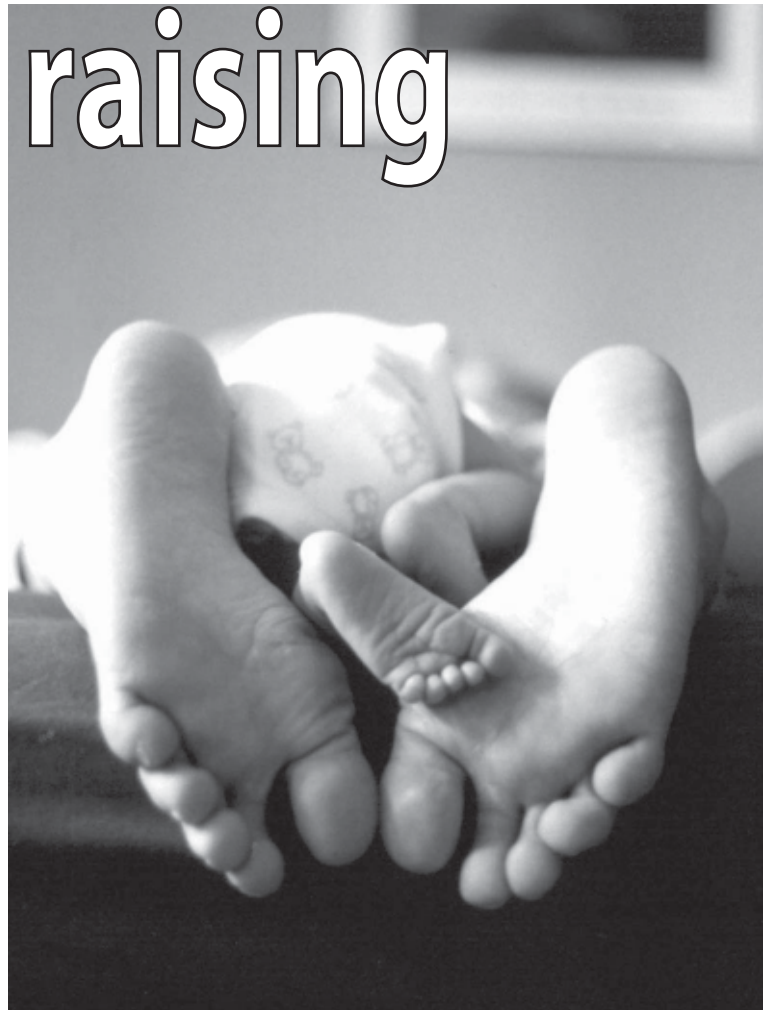
to provide information  
safely, easier.

It is advised that individuals considering pregnancy might wish to have their antiviral therapy undertaken before the pregnancy commences. These individuals should be reminded that the earliest time that is considered safe to conceive after the use of ribavirin is 6 months after the drug has been discontinued. This relates to the long half-life of the drug in the body. Numerous studies suggest that breast feeding is not a risk factor for the transmission of hepatitis C and mothers who deliver a baby are encouraged to breast feed if that is their desire.

Within any household there is a risk of transmission of hepatitis C from blood exposure and all family members need to be aware of the risk this means of transmitting hep C at all times. Families should be advised of the precautions to take to avoid accidental transmission from sharing equipment in the household that may be contaminated with blood such as toothbrushes, razor blades, hair combs etc. Wherever a blood spill has occurred the affected individual should clean that up if possible, if not, other members of the family should use gloves, paper towelling and the area should be cleaned with bleach after the blood spill has been cleared up. These actions will only minimise the risk of transmission in the household setting though, as bleach does not kill the hepatitis C virus.

## Hepatitis C treatment of a partner: risk to a pregnant woman

It is advised that female partners of males who are on antiviral therapy should not consider pregnancy whilst their partner is on treatment or for 6 months after the partner has ceased therapy. This is based on a very small theoretical risk that ribavirin could be transmitted in the semen having an adverse affect on foetal development. It is stressed that this risk remains theoretical at this stage.



## Conclusion

While there is much concern about possible adverse effects of HCV infection in the pregnant woman, it has to be stressed that much of the concern is ill-founded. HCV infected women are likely to have a normal pregnancy and the baby is most likely to be born free of the virus.

This does not mean that patients in this particular situation should not receive support, information and management of their symptoms during the pregnancy. It is imperative that antiviral therapy not be used during pregnancy. It is also critical that patients not be given advice to terminate the pregnancy so that treatment may be given. This approach is not appropriate in any patient. It is of interest that in most pregnant HCV infected patients, the ALT level is normal as the immune system tends to be less active against the virus during the pregnancy. Normal ALT levels in pregnancy should not be taken to mean the virus has been cleared. An HCV RNA test remains the only way of determining the infective status of the patient.

- › Professor Robert Batey is Area Director for Drug and Alcohol Clinical Services, Hunter and New England Health; and Tracey Jones is Clinical Nurse Consultant-Hepatitis C: Hepatitis C, Department of Gastroenterology, John Hunter Hospital, Newcastle.

# NEW GUIDELINES FOR T



**Over the years, there has been great trauma for families to arbitrarily decide on how the funeral will be carried out by the funeral industry, health services and local government to prevent this. Following our introduction we present excerpts from the guidelines.**

## Introduction

No matter our religion or philosophical beliefs, the two most central happenings in our lives are our birth and our death.

Several times in the past we have reported on family and friends being denied the last chance to view their departed loved one.

In a previous edition of *The Hep C Review* (Ed32, p15), Matthew describes his family's experience of funeral workers who acted in ignorant fear and left ongoing scars that remain today. This abridgement highlights the pain of his hepatitis C story.

I am writing about when I lost my brother. He died so suddenly that our family didn't identify him but we planned to have a viewing with him at the funeral.

With one day's notice, the funeral directors [phoned to say] "We have your son's body back on the Central Coast so the funeral is right to go ahead tomorrow as planned. But your son had hepatitis C and it is a highly contagious disease. Because you're not allowed to view a person with hepatitis C there can't be a viewing."

*It wasn't until months later [after writing to the Minister for Health] I found out that we as a family had every right to view my brother. But it is too late, my brother is buried.*

*My mother and I have suffered extra grief because of the actions of the funeral directors. All my mother wanted to do was see her son of 28 years for the last time in her life. This right was taken away.*

### Matthew, NSW

In this edition, we are able to report that as a result of letters to the Minister from Matthew and other affected families, ongoing lobbying by the Council, other related organisations and individual health care workers, and following the NSW Anti-Discrimination Board Inquiry into Hepatitis C related discrimination (C-Change), revised guidelines on funeral industry practices will now help prevent these situations happening again.

Following this introduction are excerpts from the guidelines that particularly relate to HCV and other infectious diseases.

# THE FUNERAL INDUSTRY

family and friends when a person with hepatitis C infection dies and funeral industry workers out. The NSW government has recently initiated revised guidelines to assist the funeral industry to understand and comply with the Public Health (Disposal of bodies) Regulation (2002). This article focuses on the guidelines that particularly relate to HCV and other infectious diseases.

## 4.1 Bodies to be placed in body bags

There are three main issues to be considered before a body is moved (Clauses 13 and 14). The first is to ensure that the body is bagged or wrapped securely in high quality material so that there is no risk to public health and hygiene from the body. The second is to ensure that the body is clearly identified. Thirdly, if the deceased had any disease which could be infectious or pose a risk to people handling the body, then warning labels must also be attached to the bagged body.

The Regulation specifies the material to be used for the bag or wrapping and its dimensions. A body bag or wrapping must be made of low density polyethylene film of not less than 150 micrometres in thickness. This standard has been set to ensure that the bag or wrapping will cope with the weight/strain of the body when lifting and moving, will not permit body fluids to soak through the material and will resist moisture from refrigeration or other sources from coming into contact with the body. A bag for an adult must measure at least 2.4 metres in length and 1 metre in width. A bag for a child must be at least 1.5 metres in length. If wrapping is used for an adult it must be at least 2.4 metres in length when open and flat and 2 metres in width. Wrapping for a child must be at least 1.5 metres in length.

The name of the dead person, or some other identification of the person, must be written clearly and indelibly on the top outer surface of the bag or wrapping. The responsibility for correctly bagging and labelling the body lies with the hospital when the body is at a hospital. (The definition of hospital as used in the Regulation includes nursing homes, private hospitals, day procedure centres and institutions under the Mental Health Act 1990) The Regulation states that the chief executive officer is

responsible for compliance with bagging of bodies. In practice, hospital CEOs will delegate to responsible staff. The funeral director may actually complete this task for the hospital but the hospital CEO remains responsible to ensure that the task has been done. In any other place or premise, the funeral director or other person removing the body is responsible for complying with correct bagging and labelling of the body.

An additional responsibility for the person bagging and labelling the body is to ensure the correct labelling when there is reason to believe that the body is infected with a List A or List B disease (*see over page*). In this situation the bag or wrapping must also be clearly and indelibly marked with the appropriate words either 'INFECTIOUS DISEASE - LIST A - HANDLE WITH CARE' or 'INFECTIOUS DISEASE - LIST B - HANDLE WITH CARE'. Should the original bag or wrapping be replaced for any reason, then these words must be written on the new bagging or wrapping.

### Hypothetical case

For many years, the Truly Excellent funeral Company has ... built a reputation for providing sensitive and respectful services. On several occasions they have been called to remove the body of a man who has died at home from [infectious disease such as hepatitis C]. If family and friends want to remain in the room while the body is wrapped and prepared for transfer then the funeral directors are careful to explain what they are obliged to do while wearing protective clothing and labelling the wrapped or bagged body.

*The funeral directors prefer that the family and friends should leave them in privacy to do these tasks. They also prefer that no family or friends see the labelling of the body bag with the required words for a List A disease (see over page). Once the labelling is done they completely cover the bagged or wrapped body with a plain coloured sheet and possibly a stretcher cover as well so that no labelling can be seen as they carry the body from the room, out of the home and into the vehicle.*

## 6.1 Transmission of disease and standard precautions

Bacteria and viruses which cause disease are carried on the skin and in the blood and other body fluids. Some bacteria and viruses can still be active in the body after death. This means that if any of the infected body's fluids come into contact with a person and find a way to enter their body, e.g. through a break in the skin or through the mouth or nasal cavity then there is the possibility of causing infection in that person. For most blood borne diseases (like hepatitis C or HIV) this risk is extremely small as the viruses are quite fragile and blood carrying infectious particles has to quickly enter the bloodstream before it could cause infection.

It is always possible that a person may have had a blood borne disease such as hepatitis C or HIV that was never diagnosed or recognised when they were alive. Hospitals and other settings where there is any risk of occupational transmission of infection from living people operate under the same basic principle which is to assume that everyone is potentially infectious. Therefore when carrying out any invasive procedures or exposing workers to another person's body fluids, standard precautions for infection control are followed.

Even though the risk is not large in the first instance in handling the body of a person who may have died with an infectious disease, the risk of transmitting infection can be almost entirely eliminated by following the standard precautions for infection control. Such standard precautions in the handling of all bodies, alive or dead, are a requirement under occupational health and safety legislation.

The precautions include practices like wearing gloves and other protective clothing and carefully managing waste. Detailed information is available in the *NSW Health Department Circular No. 2002/45: Infection Control Policy*.

For the purpose of the Regulation, infectious diseases which could pose some risk to people handling and preparing bodies have been divided into List A and List B diseases.

### List A diseases

Creutzfeld-Jacob disease (CJD), Hepatitis C, Human immunodeficiency virus infection (HIV).

These three diseases are grouped as List A diseases because the bodies of people known to have died with these conditions should be handled with caution and care. The actual risk of the transmission of virus after death is extremely small and is manageable by following standard precautions.

### List B diseases

Diphtheria, Plague, Respiratory anthrax, Smallpox, Tuberculosis, any viral haemorrhagic fever (including Lassa, Marburg, Ebola and Congo-Crimean fevers).

One of the features that List B diseases have in common is the potential for airborne transmission. This means that infected particles from an infected body could be breathed in by a person in close contact with the body, particularly if they are manipulating the body in such a way as to expel air from the lungs.

## ***In summary..***

*Under the previous Public Health Regulation, funeral directors should use their discretion in allowing viewings of bodies with HIV or hepatitis C. This situation led to many distressing occasions for families and friends. They had been able to touch, kiss and hold their relative or friend when they were alive but found they were denied even a final look at their body, let alone the opportunity to touch or kiss them goodbye.*

## 6.6 General management of bodies with infectious diseases

There are other infectious diseases which do not appear as List A or List B diseases. Some of them are potentially more infectious than the List A diseases. Both hepatitis B and hepatitis A are infectious. However immunisation is available against both these forms of hepatitis. Again the prevalence of these types of infections in the community is the reason to practice standard precautions when handling all bodies.

### Protective clothing

When a person is placing in a bag, or wrapping, a body that they have reason to believe has an infectious disease, the person must wear protective clothing. The Regulation (Clause 14) stipulates a clean outer garment such as a gown, overalls or jumpsuit; a clean pair of disposable gloves, a disposable mask and appropriate eye protection. Immediately after use, the wearer is responsible for ensuring that all the items are placed in a clean plastic bag. They must then be laundered as soon as practicable or if they are disposable items, they must be disposed of promptly as contaminated (clinical) waste.

## 6.7 Management of bodies with List A diseases

The Regulation puts no restriction on viewing bodies of people who have had List A infections.

When embalming a body with a List A disease or when carrying out more minor procedures to prepare the body for viewing, standard precautions should be followed in the same way as they would be in handling or doing invasive procedures on every body.

However in recognition of some concern in the funeral industry about the handling of bodies with List A diseases, the Regulation does stipulate that a person who carries out an invasive procedure (one in which the dermis is cut) must have completed certain training. They must have completed a training course, or series of courses, in mortuary practice, infection control procedures and occupational health and safety and these courses must have been approved by the Public Health Unit (Clause 12). There is a NSW Health policy in place on approval for these courses. Funeral directors should contact their local Public Health Unit to find out about the availability of approved courses.

Bodies believed to be infected with a List A disease must have the bagging or wrapping marked indelibly with 'INFECTIOUS DISEASE - LIST A - HANDLE WITH CARE' (Clause 13). Refer to Section 4 of this document on handling of bodies.

**It should be noted that the importance of this issue is mainly to do with the trauma associated with the inevitable death of loved ones who may inadvertently have hepatitis C - as opposed to the possibility of dying from hepatitis C related complications. Indeed, only about four in every hundred people with hepatitis C will face liver cancer or liver failure and in these cases, it is only after 30 or 40 years of having chronic hepatitis C.**

*C-Change, a comprehensive report from the Anti-Discrimination Board on discrimination related to hepatitis C documented these cases.*

*This was a difficult situation for the funeral directors who were acting accordingly to the regulations and believed that they were taking appropriate precautions both to protect the health of their own staff and the friends and families involved.*

*It is important to understand that under the new Regulation (Clause 16) there is no restriction on viewing bodies with HIV or hepatitis C. There is also no discretion for the funeral director to refuse a viewing on the basis of possible infection with a List A disease.*

For further information, please contact the NSW Hep C Helpline (pg 48).

› HCCNSW

# SUCCESSFULLY SURVIVING THERAPY

In November 2003, I started a twelve-month course of weekly injections of pegylated interferon together with ribavirin capsules. I knew it would be hard work. But I didn't realise how challenged I'd be by the side effects. This is about how I survived those side effects.

I'd had chronic Hep C since about 1994. I've also been HIV positive since 1985, responding well to combination ante-retroviral medication. With that background and at age 58, my specialist said I could only hope for a one-in-five chance of success.

But I was optimistic – I was fit, didn't drink, ate well and in regular employment. From my experience with the strict regime needed for HIV medications, I knew the value of a personal routine. I'd also learned about coping with the side effects of medication.

I was determined to keep on working full time. The alternative was to sit at home, thinking about how rotten I felt. Besides, I had plans for the future and continuing to work was a big part of those plans.

So I structured my life around getting to work each day, five days a week. My low energy levels were a problem. But I found that I could function better in the mornings than later in the day; and so I adjusted to that.

Encouraged by what I read in the *Hep C Review* about the experience of a Hep C positive woman benefiting from exercise, I swam three or four mornings a week – not far, but enough to give me a sense of achievement. And it did make me feel physically better.

Small amounts of regular exercise were built into my routine – very much on a trial and error basis - and in all of this, I had the professional support and advice of my hepatologist. I was able to make well-informed decisions about my treatment and its side effects. He was always ready to discuss even the most ordinary things about my routine. Better still, he collaborated with my HIV specialist on the drug interactions. Regular blood tests ensured that my drug intake was altered when necessary.

Still, work remained the focus of my routine. I had to ensure I always had plenty of sleep every night. Yes, it was dull – family and friends knew not to ring me up after 8 pm, because I'd be in bed and wouldn't answer the phone. In this, and in so many ways, they were all supportive. So were my work colleagues. All of them had to put up with my grumpiness and whinging about how rotten I felt. And if I just couldn't get out of bed, I stayed put until the energy levels rose again.

It was the longest twelve months I've experienced. But all the time I stuck to my routine and believed in a successful result. I continued to make plans for overseas travel and doing some more study down the track. And what a Christmas present I had! Two months after completing the injections, I remain clear of Hep C.

There is now every chance I'll clear the virus permanently from my system. This makes all the planning and sticking to a dreary routine worthwhile. Those twelve months were hard for me. But I proved to myself that I could do whatever was necessary to get that result.

> **John, NSW**

