The Hep C Review

Autumn Issue March 2004 Edition 44

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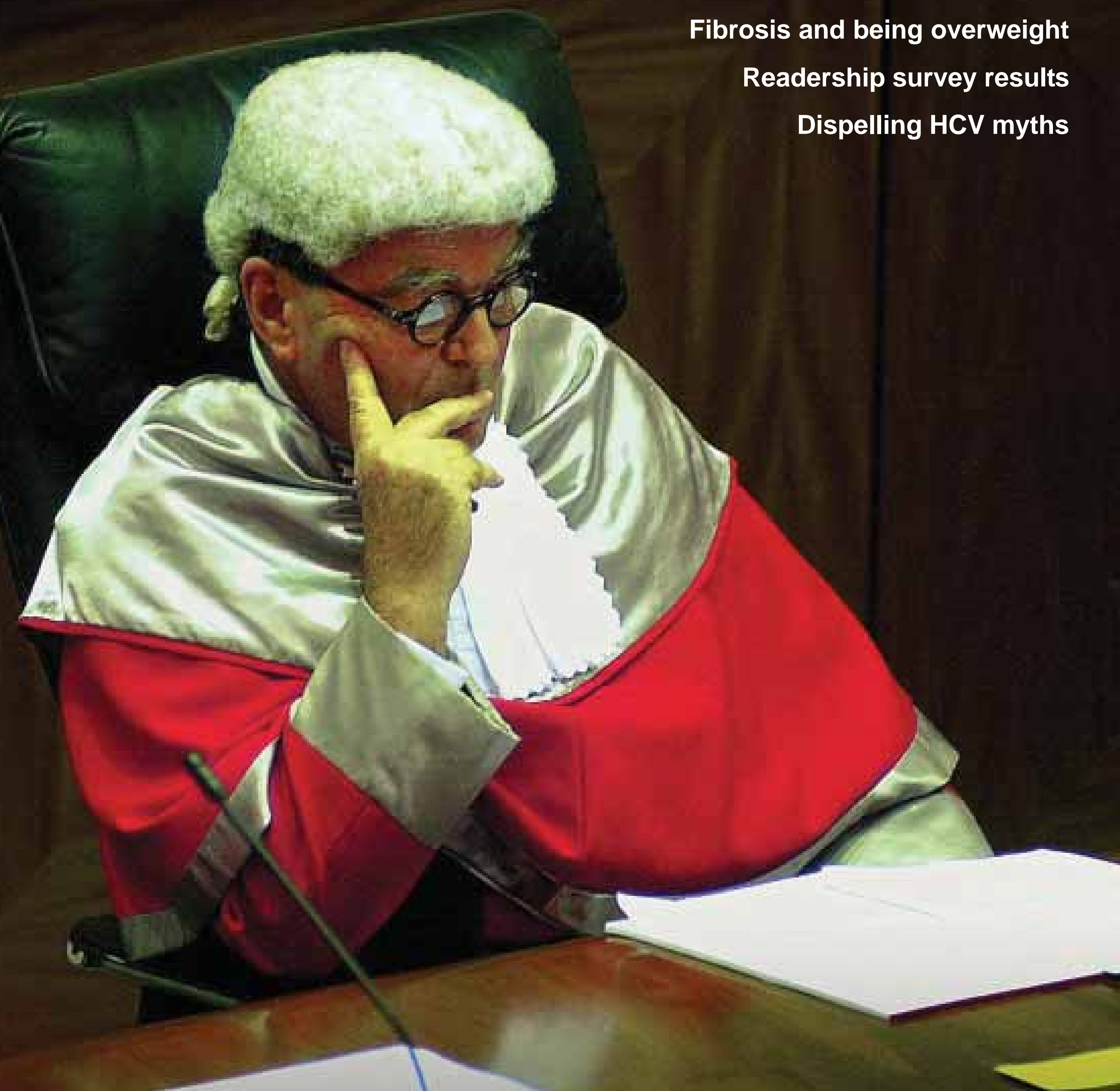

Drug addiction and Disability Discrimina

Senator Brian Greig warns of social turmoil and a legal minefield in the face of government plans to unfairly target drug users.

I wish to draw attention to the Government's proposal to exclude people addicted to illicit drugs from the Disability Discrimination Act.

This is an issue to which all fair-minded Australians, properly informed, would respond with concern and dismay.

The Prime Minister says he does not believe addicts should be protected from discrimination.

The Attorney General says anyone voluntarily engaging in behaviour resulting in a disability must take personal responsibility.

The Australian Chamber of Commerce and Industry (ACCI) which lobbied for the change says it supports sensible laws protecting the genuinely disabled.

On the face of it, the Government's argument is a simple one.

Drug addicts break the law, by choice, and in doing so, forfeit their claim to protection from discrimination, especially in the workplace. An employer should be able to sack or refuse to employ someone if they have an addiction.

Not only is this simple argument based on false premise, but it hides a more complex reality.

If we can accept that addiction is a disabling force - is a disability - then claiming the right to be able to discriminate against people on that basis becomes a difficult position to defend.

In defining disability, the Human Rights and Equal Opportunity Commission draws on medically accepted diagnostic protocols that clearly include substance addiction within the definition of a 'disorder'.

The Disability Discrimination Act considers impaired capacity without regard to cause. Acquired brain injuries, mental health issues and other impairments that can arise from substance use, whether legal or illegal, are protected under the Act to the same extent as those arising from any other cause.

By contrast, temporary loss of capacity through intoxication does not fall within the definition of a disability, because the Act makes a medically significant distinction between 'disorder' and 'condition'.

Contrary to concern expressed by the ACCI, this means anyone dismissed for workplace intoxication has no recourse under the Disability Discrimination Act. This is very clear.

The view that the Disability Discrimination Act creates or bestows additional rights to which addicts should not be entitled also cannot be supported. Anyone who is unable to perform the inherent aspects of their job can be reassigned or sacked, whether they have a disability or not.

What the Act currently does do, is protect people from less favourable treatment that is not reasonable or justifiable - it ensures a level playing field, equality of access, and judgement on individual merit.

The Prime Minister's proposal will prevent this.

It will legalise discrimination in employment, accommodation, education, provision of goods and services and club membership. It removes the necessity in law to ensure people with addiction to illegal substances are treated with respect, dignity and equality and in doing so, undermines the basis upon which our fair and democratic system is built.

Actively excluding a group from discrimination protection places it at immediate risk. This simple act invites those with any number of moral or ethical views to act out their value-laden objections, and to do so with the full support of the law.

Front cover photo of Justice David Angel by Patrina Malone, courtesy of NewsPix.

the
tion Amendment Act

The possibility that people of any age could now also be legitimately sacked for experimental drug use when not even at work is completely outrageous.

Will excision of addiction from the Disability Discrimination Act also open the possibility of restricted or non-existent protection to people on the basis of suspected addiction?

In a recent *Bulletin* article, a caravan park landlord says:

> *"We're not educators, social workers, we just rent vans. If they come in here and they've got bad teeth or sores over their face, you know they're on go-ey so you don't take them."*

It's already happening. People are in such dire poverty that they can barely afford basic accommodation, let alone new teeth, and they are refused access on the assumption they're addicts.

This is an appalling dismissal of human rights, and the Government is seeking to legitimise it.

To add to the human rights and definitional problems contained in the proposal, there is the further problem in that it only references addiction to illegal drugs.

By creating a distinction between classes of drug, the Government's real agenda, if there were ever any doubt, becomes clear: it says that rather than addiction per se being the issue requiring clarification, it is the illegality of the substance that causes problems for those seeking to discriminate.

How can an employer possibly justify claiming the right to dismiss an employee addicted to an illegal substance but not to a legal one.

This proposal reduces the incentive to seek treatment, for fear of dismissal or eviction, which in turn is likely to result in increased overdoses, mental and other health complications, HIV and hepatitis transmission, and other social and family problems.

The Government thinks because it is picking on the substance addicted, no-one will notice. I do not believe ordinary Australians would countenance this lack of compassion.

A simple analogy would be if a drink driving conviction was used as grounds for dismissal or eviction, even if it had nothing to do with either your place of work or residence. This would cause an outrage.

The Prime Minister is attempting to drive a wedge between the 'deserving' and the 'undeserving', the 'genuinely' disabled and 'others', by claiming that inclusion of those with self-induced impairment undermines protections to those with 'real' disabilities.

I ask, what is the difference? Drug addiction has common characteristics regardless of whether one is receiving treatment, or is addicted to legal or illicit substances – and all are deserving of equal protection under the law.

The Act does not confer special rights – IT PROTECTS PEOPLE WITH DISABILITIES FROM LESS FAVOURABLE TREATMENT THAT IS UNREASONABLE OR UNJUSTIFIABLE.

People with addictions often become so as a consequence of social isolation and exclusion. Further and deliberate exclusion will only worsen their circumstances and those of the entire community.

For these reasons the Australian Democrats strongly support the referral of this Bill to a committee inquiry to ensure full community debate about the important issues it raises.

■ Senator Brian Greig represents Western Australia and is a member of the Democrats.

The Democrats and Greens successfully debated that the Government's Bill be referred to the Senate Legal and Constitutional Legislation Committee for inquiry and report by 25 March 2004.

(Also see page 16.)

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Top police deny honey pot claims

One of New South Wales' most senior policemen denies the supervised heroin injecting room in Sydney's Kings Cross is sending the area's drug trade out of control.

Assistant Police Commissioner Dick Adams says the Kings Cross local area commander Dave Darcy has been misquoted in a newspaper article in which he claims drug dealing will never be eradicated in the Cross. The article claims 800 drug deals are done daily near the injecting room.

"It is not a honey pot effect as has been described," Assistant Commissioner Adams said.

"The independent research shows in the two years that Superintendent Darcy and his team have been working at Kings Cross with the MSIC that reported crime is down by 50 per cent."

■ Abridged from *ABC News* (undated)

Cure for people with coinfection

(USA) People who suffer from hepatitis C as well as HIV now have the highest ever chance of a hepatitis C cure through a new combination therapy, according to a new study.

The study, presented at a scientific meeting in San Francisco last week, is good news. It found a combination therapy using the drugs Pegasys and Ribavirin achieved a record 40 per cent cure rate for co-infected patients, compared to 12 per cent with conventional therapy.

Levinia Crooks of the Australian Society for HIV Medicine said the results from the study enabled people with HIV to undertake treatment for their hepatitis C with the confidence that it would not effect their HIV treatment.

■ This article was abridged from *The Age*: www.theage.com.au/articles/2004/02/16/1076779866919.html

Labor debates injecting rooms

The federal ALP wants to "support and promote" heroin injecting rooms, despite every Labor state except NSW backing away from the idea.

The proposal, included in the draft Party Platform to be debated at Labor's national conference later this week, comes after the Carr Government agreed to extend the trial of the nation's first legal injecting room, in Sydney's Kings Cross, after it was found to have saved several lives.

The ACT was set to follow NSW in having a supervised heroin injecting room, but recently shelved the idea. All other states have so far backed away from the politically contentious issue.

The draft platform states that Labor's illicit drugs strategy will "support and promote ... state government initiatives, such as supervised injecting places, aimed at reducing the costs to the community of illicit drug use and which will provide access to counselling and rehabilitation and facilitate scientific and medical research".

Prime Minister John Howard and the chairman of the Australian National Council on Drugs, Major Brian Watters, are strongly opposed to heroin injecting rooms.

But Dr Alex Wodak, director of alcohol and drug services at Sydney's St Vincent's Hospital, welcomed the move, saying Canada and Western European countries had acknowledged the need for injecting rooms, which helped manage overdoses and reduced the risk of the transmission of diseases.

■ Abridged from *The Australian*, 28/01/04

Want to know more about your diet, metabolic rate and body composition?

The Albion Street Centre is running a study looking at dietary intake, metabolic rate and antioxidant levels in people with hep C - and how this relates to blood measures (such as liver function, blood sugar and blood fats).

If you are interested in participating in this study please contact the Nutrition Unit (Louise or Simon) at the Albion Street Centre on 9332 9600. The study involves one two hour visit to the Albion Street Centre in Surry Hills, Sydney.

■ ASC

Inmate bites officers

(USA) Officials are monitoring two Oklahoma County detention officers after they were bitten by an inmate who tested positive for hepatitis C. The guards, whose names have not been released, were bitten by a female inmate. They returned to work hours later, Capt. Kelly Marshall said.

"We will continue to monitor them for at least a year and longer if the physicians tell us to," Marshall explained.

The 25-year-old inmate was arrested earlier in the day on complaints of driving without a license and having no insurance verification.

"She raised her hand to assault the officer and then threw herself to the ground to resist being placed in her cell," Marshall said.

The inmate bit officers and said she had AIDS. She did not test positive for HIV, but she did have hepatitis C, a disease that can affect the liver.

An inmate has assaulted an officer with a bodily fluid at least 10 times in the past year, Marshall said. Bites are less common and so far an officer has never developed a disease after an attack.

The inmate could face assault and battery charges.

■ Abridged with thanks from a *Daily Oklahoman* article via http://www.hcvadvocate.org/

Screening an option in USA in 1980s

(USA) Guardians of the United States blood supply gathered in 1981 at American Red Cross headquarters to consider a way to prevent nonA nonB (hep C) from spreading through transfusions.

For several hours they talked about using a test that was available and could help screen out blood carrying the virus.

The ALT test (part of current liver function testing) was far from perfect. But evidence that it would show a disease infecting hundreds of thousands of patients each year seemed so persuasive that the blood industry needed to act.

The group concluded that "Blood collection agencies in the US should prepare to test ALT levels of all blood units."

But that did not happen. In fact, the blood industry would delay testing in the USA for six more years.

It is impossible to know how many hepatitis C infections could have been prevented by the ALT test during those years. But that figure might be more than 300,000 people, based on data from some studies.

■ Abridged with thanks from a *Kansas City Star* news article.

Average Irish hep C payout at €310,000

(Ireland) The average payout to those in Ireland who contracted hepatitis C infection from infected blood or blood products has now risen to €313,180.

A tribunal has been hearing compensation cases in private since 1997 after it was set up in the wake of the tribunal into the contamination of the blood product Anti-D.

A significant number of people are just opting for provisional awards, which allows them to take some compensation now and return in the coming years for more if their condition deteriorates.

The scheme helps reduce the legal costs which would mount up if each person took their claims to court.

■ Abridged with thanks from an *Irish Independent* news article via the HCV Advocate website.

New name for top body

The national strategic body that deals with hep C has recently undergone changes.

Its name has been altered from the Australian National Council on AIDS, Hepatitides & Related Diseases (ANCAHRD) to the Ministerial Advisory Committee on AIDS, Sexual Health and hepatitis (MACASHH).

Previously chaired by Chris Puplick, it is now chaired by former Federal Minister for Health, Michael Wooldridge.

■ HCCNSW

Complaints?

If you wish to make a complaint concerning our products and services, please visit our website for more information: www.hepatitisc.org.au/documents/ComplaintsPolicy.pdf

UK payouts announced

(UK) Health Secretary John Reid announced that the UK Department of Health will make payments to everyone in the UK who has been infected with hepatitis C through NHS treatment with blood and blood products and was alive on 29 August 2003.

The main features of the scheme are as follows:

- People infected with hepatitis C will receive an initial lump sum of £20,000
- Those with advanced liver disease (such as cirrhosis, liver cancer and post-transplantation) will receive an additional £25,000
- Those who have cleared the virus on treatment are included
- Those who are also infected with HIV are included
- Those who were infected as a result of the virus being transmitted from someone who was infected by blood/blood products are included
- Those who died from whatever cause of death before 29 August 2003 are excluded
- Those who cleared the virus through their own immune system in the acute phase of illness, will be excluded
- An independent scheme, the Skipton Fund, will administer the payments and will start operating in April 2004
- Payments to eligible claimants will follow after April 2004

■ UK National Health Service press release.

New staff at Hep C Council

Over the last two years, Joan Silk has played an enthusiastic role in developing the Council's education and *C-een & Heard* Speakers services.

Looking for new challenges, Joan has left the Council to take up community development work in Western Sydney.

Kimberley Clarke has filled Joan's role, coming to us from the HCV prevention / harm minimisation sector. Kimberley worked at an NSP in Northern Sydney Health, primarily with injecting drug users. She was strongly involved in community development and health promotion activities aimed at increasing access to health and welfare services for people who inject drugs.

■ HCCNSW

New staff at AHC

Danielle Elston left the Australian Hepatitis Council late last year. Her contract involved developing the Australian Hepatitis Council's relationships with journalists and various federal MPs.

The position in which Danielle was employed has been renamed as the National Communications and Policy Officer to reflect the needs of the organisation and the sector.

The position was advertised and interviews held. Jeff Ward, the previous Coordinator of the Hepatitis C Council of Queensland was successful in his application for the position and he commenced with the Australian Hepatitis Council on the 6 January 2004.

■ AHC

Human tests for hepatitis vaccine

(USA) A vaccine to prevent infection by the virus that causes the liver disease, hepatitis C, is to be tested on humans in trials to be conducted by Saint Louis University, USA.

Lead researcher Dr Sharon Frey said: "A vaccine to prevent the infection would be an important breakthrough in controlling the spread of the virus."

Grant McNally, chairman of the UK Assembly on Hepatitis C, told BBC News Online an effective vaccine would be welcome.

But he warned that it should not lull people into a false sense of security. Avoiding sharing drug-taking equipment was still vital, he said, as a vaccine was probably still years away.

Professor Graham Foster, a consultant hepatologist at the Royal London Hospital, agreed, saying, "My feeling is that this could be a very important step on the way to a vaccine, but I would be surprised if it turns out to be the final answer."

"I suspect it will need tweaking to find the final approach, but this study will certainly produce a lot of helpful information."

The study is being conducted by St. Louis University's Center for Vaccine Development, led by the Division of Infectious Diseases and Immunology, in collaboration with St. Louis University Liver Center, led by the school's division of Gastroenterology and Hepatology.

The research is sponsored by Chiron and the US National Institutes of Health.

■ Abridged with thanks from a BBC News item.

Jury sides with Deborah

(USA) A jury awarded a woman $551,600 Wednesday after finding she likely contracted hepatitis C from a San Antonio business that performs permanent cosmetic applications.

While medical studies have linked the virus to tattoo parlors and related permanent cosmetic businesses, the lawsuit is believed to be the first time nationally that the issue has gone to trial, allowing a jury to make the link, state and national health experts said.

"We have no confirmed records of hepatitis C being transmitted at a licensed studio, so we're certainly interested in this case," said John Gower, director of programs for drugs and cosmetics at the Texas Department of Health in Austin.

The jury found Permanent Cosmetics negligent for infecting Deborah Anderson, who received a series of permanent colouring touch-ups to her lips at the studio, mostly in 1999.

Anderson, 52, learned she had hepatitis C in February 2000 when a blood bank rejected her donation, according to her lawyers. During an earlier donation, she did not have the virus.

She complained to the state Department of Health, and an inspection of the business found several violations, including dirty floors in the tattooing area, employees not washing their hands between applications, and incorrect or insufficient labelling of sterilised equipment.

"The jury has sent out a message to the public about the seriousness of the health issues involved with tattooing," said LoAn Vo, one of Anderson's lawyers.

■ Abridged with thanks from a *San Antonio Express-News* article via http://news.mysanantonio.com

Killer inspires drive against hep B bias

(China) Zhou Yichao, rejected for a public servant job in Jiaxing because he tested positive for hepatitis B, killed one official who denied his application and seriously wounded another. The plight of Zhou, now on death row, has inspired a national movement against discriminatory hiring practices and lack of legal redress.

More than 120 million people in China, about 10 per cent of the population, are chronic carriers of hepatitis B. Many, like Zhou, show no symptoms and should not pose a threat to co-workers. Hepatitis B is spread through the exchange of bodily fluids and cannot be contracted through casual contact such as shaking hands. Hepatitis B can lead to liver failure and death. More than a million people die from it every year, about a third of them Chinese.

Zhang Xianzhu, another recent college graduate rejected by a state employer after his hepatitis B test, filed the country's first discrimination lawsuit against the government.

"I wanted to do something for this community," Zhang said. "I did it because there are so many people like me locked out of jobs and rotting in their little dark corners of the world. We face a crisis of survival."

"We are talking about people driven by the power of despair," said a hepatitis B carrier who would not reveal his name for fear of jeopardising his job.

"Without work, how can we survive? Society has to do something to reduce the social pressure and preserve our basic human rights."

■ Abridged with thanks from a *Los Angeles Times* article via www.hcvadvocate.org

New liver hit by power blackout

(USA) Since August, every time the telephone rang, Delyla Torres hoped it would be Mount Sinai Hospital, telling her it was time for her second attempt transplant operation.

Delyla's wait dragged out when an initial operation was cancelled at the last minute due to a power failure.

As she lay waiting to be wheeled into the operating room at Mount Sinai, the lights went out, in what became the largest blackout in North America. Though the hospital had its own generator, Dr. Roayaie decided it was not safe to begin such a long, complicated operation on backup power.

Months later, another liver became available and a successful liver transplant went ahead.

Delyla had cirrhosis and liver cancer, caused by hepatitis C. As she waited for another liver, she grew more anxious and her health declined. A transplant was her only hope, but she feared the cancer would spread before an organ became available, making her ineligible for the operation.

Despite the added delay in finding a suitable donor, her surgeon, Dr Roayaie said the outlook for Delyla was good.

■ Abridged from a *New York Times* article, via www.hcvadvocate.org

UK injecting centres proposed

(UK) Special centres where people with drug dependency can inject themselves under medical supervision should be introduced in the UK, two health experts said today.

The centres, which have proved successful in other countries, mean that nursing staff are on hand to deal with overdoses and other complications.

They can also give safer injecting advice, but do not supply drugs or help users to inject.

Writing in the British Medical Journal, Dr Nat Wright and Charlotte Tompkins of the Centre for Research in Primary Care, Leeds, said the centres should be piloted in the UK as part of an integrated public health strategy.

"We believe that such a clinical approach is not condoning or promoting drug use," they said. "Indeed, similar arguments were used against needle exchange programmes in the 1980s [but] such programmes are now part of accepted best practice and have demonstrably improved public health."

The home affairs select committee recently recommended that a pilot scheme of injecting houses for heroin users should be "established without delay."

But the home secretary, David Blunkett, rejected the proposal, saying injecting centres would be supported only as part of a heroin-prescribing program.

The researchers said Mr Blunkett should think again, as evidence from an Australian scheme showed that lives had been saved, there had been no increase in hepatitis infections and more clients had started treatment.

They added that the centres reduced the risk to the general public by cutting the numbers injecting on the street and the projects targeted homeless and socially excluded individuals.

"We have not got any plans to pilot injecting rooms." A home office spokeswoman said. "We keep an eye on all international and UK research but in Britain at the moment we have other methods of reducing harm, such as needle exchange programmes."

■ Abridged from a *Guardian* article via http://www.guardian.co.uk

Drug dependency rights set off rebellion

Attorney-General Philip Ruddock suffered a backbench rebellion after two colleagues spoke out against a plan to strip people who are dependent on illicit drugs of anti-discrimination protection in a recent party room meeting.

Mr Ruddock has recently introduced an amendment to the Disability Discrimination Act to make it legal for employers, landlords and clubs to discriminate against people with a drug dependency.

The plan has been criticised by experts who say it could perpetuate drug dependency by depriving people of the chance to improve their lives.

NSW Senator Marise Payne told colleagues she reserved her right to vote against the bill, describing it as unfair. She was supported by Victorian backbencher Petro Georgiou, who spoke against the legislation but did not threaten to cross the floor.

The plan follows a Federal Court case in which a NSW man, dependent on heroin and undergoing methadone treatment, successfully claimed he was being discriminated against after his local RSL cancelled his membership.

Prime Minister John Howard subsequently asked Mr Ruddock to amend the law to make it clear drug dependency was not a disability.

Speaking against the bill, Senator Payne said it was wrong to withdraw protections from dependent people when there weren't enough spaces available in drug rehabilitation programs to give every one of them a chance to help themselves.

Alcohol and Other Drugs Council of Australia CEO, Cheryl Wilson, said stable jobs, housing and social opportunities could help users beat their dependency.

"The majority of people who use illicit drugs are young people. They are trying to find jobs, education, housing," she said. "There is a real concern that it (the amendment) is going to perpetuate a person's problems rather than giving them the opportunity to move on."

■ Abridged with thanks from *The Age*, 03/12/2003

Following opposition from the Democrats and Greens, the amendment has been referred to the Senate Legal and Constitutional Legislation Committee for public review. Also see editorial, page 2 and article, page 16. Ed

Haemophilia gene therapy

Australian researchers are pioneering a novel treatment for haemophilia. The technique involves injecting a healthy gene into the patient's liver.

Chris was born with severe haemophilia. It is caused by a variation in a gene which prevents blood from clotting properly, leading to bruising and severe bleeding. He is the first Australian to take part in a gene therapy trial for the condition.

"I thought it was interesting, a novel approach and it sounded quite exciting," Chris says.

Dr John Rasko from the Centenary Institute and Sydney Cancer Centre at Sydney's Royal Prince Alfred hospital is pioneering the new treatment. A healthy version of the haemophilia gene was injected into Chris's liver to replace the damaged one. It follows successful trials of the technique on animals.

"It really is quite striking: after a single injection animals with haemophilia have effectively been cured and stay that way for many years," Dr Rasko says.

While the levels of clotting factor in Chris's blood have gone up and down, overall his symptoms have improved.

"Statistically I may have had fewer bleeds. I may have gone from one every two to three weeks to one a month," Chris says.

If successful, there is optimism that scientists may be able to use the gene therapy approach for a range of genetic diseases including cancer.

■ Abridged with thanks from *ABC News Online*: http://www.abc.net.au/news/health/sophie_scott/newsitems/s988609.htm

Drug makers target hep C market

(USA) Eighteen months before Hoffmann-La Roche Inc. launched its advanced hepatitis C drug Pegasys, the drug company began reaching out to physicians who treat the tough-to-cure virus.

That strategy helped the company grab half the market in barely a year from Schering-Plough, which had nearly a two-year lead with its Peg-Intron.

"We knew we were playing catch-up," said George Abercrombie, chief executive officer of Hoffmann-La Roche, the US subsidiary of Switzerland's Roche Group.

"This company was focused like a laser around the launch of Pegasys", he told The Associated Press.

Besides hiring more sales representatives focused on the 15,000 US doctors specialising in hepatitis treatment, the company gave 12-week supplies of Pegasys free to about 12,000 patients. It also offered wholesalers a 43 percent discount on Copegus, its brand of ribavirin, an antiviral pill taken with the interferon to boost its effectiveness.

Sales grew quickly and Pegasys soon had captured 50 percent of the market from Peg-Intron, with about 19,000 prescriptions dispensed for each. That's a tiny fraction, though, of the estimated 4 million Americans infected with hepatitis C, most of whom aren't being treated because they don't know they're infected or can't afford US $25,000 for a course of treatment.

Meanwhile, Schering-Plough erred in cutting its sales force 10 percent. Now under a new CEO, turnaround whiz Fred Hassan, Schering-Plough is fighting to win back revenues for what is now the company's biggest franchise.

■ Abridged with thanks from an *AAP* news article, via www.hcvadvocate.org/

UK goes combo

(UK) Thousands of patients with hepatitis C will be switched to more effective and expensive treatments. The decision was announced as the government steps up its battle against hepatitis C, a condition which has shown alarming increases over the last decade.

Official endorsement for the drug pegylated interferon, taken in combination with ribavirin, could significantly increase the drugs bill for fighting one of Britain's most serious public health threats.

Only about 2,000 patients are thought at present to use standard interferon and ribavirin, but that number is expected to grow rapidly.

Conservative estimates put the extra cost at around £11m a year.

Graham Foster, consultant hepatologist with the Royal London NHS trust, reported it was the first positive step which will allow patients in the UK to receive the same treatment choice which has been available to patients in other parts of the world for many years.

■ Abridged from *The Guardian*, 28 January, 2004, via http://www.hcvadvocate.org/

Portugal’s possible prison injecting rooms

(Portugal) A recently released government report recommends Portugal set up heroin injection rooms in prisons, where widespread drug use is leading to rising HIV rates among the nation’s 14,000 inmates. Nearly one in two Portuguese prisoners uses drugs and of those who do, 26.8 percent use injecting drugs like heroin, said the report.

Alarmingly, the report concluded that more than three-quarters of those who use injecting drugs behind bars share their needles, creating an ideal environment for the spread of HIV.

Compiled by the office of Portugal’s justice ombudsman, the report says 14 percent of prisoners are infected with HIV. Along with other communicable diseases like hepatitis C, the prevalence of HIV/AIDS helped give Portugal the highest rate of prisoner deaths in the European Union last year.

To slow the spread of HIV and cut the death rate among prisoners, the report recommended the government set up injection rooms where inmates would be provided with clean needles and a place to inject in a supervised setting.

The recommendation was immediately backed by Portugal’s lawyer’s association and by former UN General Assembly President Diogo Freitas do Amaral, who currently chairs a commission on prison reform in Portugal.

“There are unique circumstances in prisons which can lead one to adopt a different approach to drugs than that which is adopted in the wider society,” he said just after the report’s release.

Fernando Negrao, head of Portugal’s Drugs Institute, a branch of the health ministry that tackles drug dependency, argued that injection rooms could be effective but only after prisons become less crowded.

- Abridged with thanks from *Agence France Presse* via http://www.hcvadvocate.org/

UK ban on Qian Bai Pian

(UK) British regulators are proposing a ban on the Chinese herbal remedy Qian Bai Biyan Pian in the interests of public health.

The Medicines and Healthcare Products Regulatory Agency said the unlicensed product, which is sometimes used for rhinitis, could contain the Senecio plant, which can cause serious liver damage.

The agency received five reports indicating the product was still being supplied to the public, despite its call in 2002 for a voluntary market withdrawal.

- Abridged with thanks from a *Reuters Health* article via http://www.hcvadvocate.org/

The crisis in health care

The real crisis in Australian health care is the totally inadequate attention being given to the development of long-term goals and coordinated strategies, writes Peter Sainsbury.

For years I have repeated endlessly, 'There is no Australian health care crisis. Australians enjoy very good health. Australia has a very good health system. Australians like Medicare. Medicare has some problems, which need fixing. But ... there is no crisis!'

Recently I have reconsidered. There is a crisis looming. But it isn't dollars or waiting lists or nurses or Emergency Departments or GPs or even medical indemnity. And it isn't the continuing appalling state of Indigenous health, or cancer, or the epidemic of obesity, or SARS.

No, the real crisis is the totally inadequate attention being given to the development of long-term goals and coordinated strategies for Australia's health system.

The division of powers between the Commonwealth and State governments has created problems since Federation, not only in health care. But it seems that the longstanding cooperation, willing or unwilling, between the jurisdictions is being replaced by health ministers preferring to blame each other publicly for the symptoms of poor planning and poor coordination ('he can't run his state's hospitals efficiently'; 'she doesn't support bulk-billing') rather than by working together to create a first-rate system. The result is an increasingly confused, confusing and dysfunctional health system that will eventually fail to deliver good health and good health care for all Australians.

So why is this and what can be done?

Firstly, the split responsibilities, grounded in the Constitution, are a major hurdle. Simply, almost all Commonwealth and State health funding originates from the Commonwealth Government, who also directly pay GPs and specialists and funds the Pharmaceutical Benefits Scheme (which doesn't include drugs provided in hospital). The states provide the hospital and community health services, including health promotion.

We must move to a simpler, less fragmented system. The Commonwealth controls the money, so maybe they should be responsible for providing all the services.

Secondly, despite its rhetoric, the current Commonwealth Government is deliberately dismantling Medicare. It is misrepresenting the aims of Medicare. It is shamelessly wasting over two billion dollars a year on the totally ineffective private health insurance rebate. It is redefining bulk-billing to destroy its purpose. It is entering into trade agreements with other countries (particularly the United States) that seriously threaten the effectiveness and excellent cost control record of Australia's health care system.

Why the government would destroy a cost-effective, internationally admired system to create a more fragmented, more costly one is totally beyond me. Anyone who cares about good health, health services available on the basis of need not ability to pay, and the efficient use of taxpayers' dollars must oppose this underhand destruction of Medicare.

Thirdly, forces whose primary interest is neither improved health nor improved health care are driving many of the current developments in Australia's health care system: reduced direct taxation, international trade agreements, doctors' salaries, corporate profits, cost-shifting, political point-scoring, professional rivalries. This is compounded by an all-too-frequent focus by politicians and the press on meaningless debates about inputs ('we're spending more on health than the previous government') and bed numbers rather than service quality, value for money and creating better health.

Fourthly, health departments across Australia have plans for every conceivable service, population group, illness and risk factor. We also have the Australian Health Care Agreements between the Commonwealth and State Governments. But these are like railway carriages with no engine and no track. We need a national plan, agreed by all jurisdictions, that clearly specifies the overall goals of the health system and the strategies to achieve them.

The national plan should include more emphasis and more funding for health promotion. This is a wise investment. Also, it must be developed in consultation with the community, which knows what it needs and what it is prepared to pay.

Such a plan will not be developed overnight and it will involve many compromises. But the real crisis is looming, and those who should be taking it seriously, the politicians and health departments, are ignoring it. The alternative, continuing to undermine a good but not perfect system, will have disastrous consequences for all Australians.

■ Peter Sainsbury is president of the Public Health Association of Australia.

Abridged from a transcript of the ABC Radio National program, *Perspective*, 14 January 2004.

The Opal Miner

I was born in Sweden 55 years ago. I started doing a bit of drugs under the hippy era in the late 1960s. But this only lasted for a year, and life went on. In 1986 I came to Australia and ended up trying my luck as an opal miner in Lightning Ridge. I was working underground with a few candles and a handpick. The first week I found opals that I sold for $3000. My God this was great. I had not made that kind of money in my whole life in a week. I invested the money in better machinery, and now 18 years later I am still digging for the beautiful gem.

I have been one of the lucky ones, and have made good money from the opals I have found. I have been able to buy myself a house on the coast with ocean view and have a very good life.

Six years ago I started feeling that something was wrong with me. I went to different doctors and had blood tests done. They told me that I must be drinking too much. My ALT level was 180. But I was only drinking a few beers a day. And I can tell you that you need that up in Lightning Ridge where it gets up past 45 degrees in summer.

Two years ago a doctor in Dubbo found out that I had hepatitis C. Because I had my summer house in the Hunter area I got a referral to John Hunter Hospital. I had a referral to see Professor Batey. My liver biopsy showed I was 2 on the scale. They wanted me to start on combination treatment as soon as possible. The worst thing was that I had genotype 1b.

I started the treatment 18 month ago. The nurse, Tracey, helped me to take the first needle. I was a bit afraid because I knew that the treatment was going to be tough.

And yes, the treatment was very hard for me.

I got depressed and also had thyroid problems and sleeping problems. I think that I even got a bit of personality change. But I had made up my mind to fight the problems. I had great support from the whole team at John Hunter. At home I had my wonderful wife who was helping me. During my treatment my best friend passed away after a liver transplant because of hep C and that helped me a bit to keep fighting.

I responded well to the interferon. After 4 weeks my ALT level was down to 25. And it stayed there during my one year treatment. After six months they could not find any virus in my blood. Now six months after the treatment stopped they can still not find any virus.

So I have had hepatitis C genotype 1b for more than 35 years and responded well to the treatment. So never give up hope to get well. OK, the treatment was a bit hard, but it was well worth it. Now I can go on with life and hopefully find more opals, and have a great time at my house by the ocean.

I would like to really thank all the staff at the hep C unit at John Hunter Hospital.

■ **The Opal Miner, Lightening Ridge.**

Above photo of a miner (unrelated to this story) by Marc McCormack, courtesy of NewsPix. Opal graphics courtesy of Opals Australia.

New minister tows out the tough line on hcv transmission

Lisa Waller reviews media reports and interviews in an exploration of the government's position on HCV prevention.

When Tony Abbott stepped into the federal health portfolio last year one of his first jobs was to push the Government's tough on drugs message in response to a review commissioned by the Government that was critical of its strategy for combatting hepatitis C.

The review found hepatitis C is not a straightforward issue and called for more consideration of safe injecting rooms and decriminalisation of drugs, but Mr Abbott's answer was simple: "The best way to avoid hepatitis C is not to use drugs," he told Channel 10's Meet the Press in November.

In an interview on the ABC's *PM* news program in November, Mr Abbott was unrepentant about the Government sticking with its "Tough on Drugs" strategy and rejected the review's call for more consideration of safe injecting rooms and decriminalisation of drugs.

"The best way to minimise harm is to not use drugs and this Government believes that the only safe way to use drugs is to get off them altogether and that's our position and that's not going to change, Mr Abbott said."

The interviewer pointed out that the Government's own committee of experts who produced the review concluded on the evidence that harm minimisation strategies were effective ways to combat hepatitis C.

"There are things that we need to do to try to get people off drugs and under the tough on drugs policy we've got a range of treatment and rehabilitation programs, diversion initiatives, needle exchanges and so on," Mr Abbott said.

"But at the end of the day we want to get people off drugs. We don't want them to keep using drugs in a slightly less unsafe way, because there is just no safe way."

Labor's Health spokeswoman Julia Gillard was critical of the Government's response.

"There certainly is a link between injecting drug use and [hepatitis C] and the experts who went on the review committees for the Government considered that link and considered ... a harm minimisation strategy which brought drug users into contact with health authorities was the best way forward. The Government has simply not even dealt with that," Ms Gillard said.

When Mr Abbott was asked on *Meet The Press* in November if he would "go down the path of more safe injecting messages" to try to prevent the 800,000 infections estimated by by 2020, he responded: "Look, I will do whatever I can ... but in the end, a lot of these things are a function of personal behaviour and we can't by a magic wand, as it were, change personal behaviour."

He said the best way to avoid getting hepatitis C "is not to use illegal drugs, not to inject yourself with things which are illegal."

"I would urge people to take the same hardline view on that kind of lawbreaking as we do on other kinds of law breaking."

It was pointed out that this was the approach that the Government had been taking for seven years and with hepatitis C infections rising by 45 per cent. When asked if the Government's approach had failed, Mr Abbott replied that it was "working".

"Well, certainly in other areas it's working very well," he said.

"For instance, heroin deaths have dropped ... thanks to the Tough On Drugs message ... so personal behaviour does matter, and frankly, there are things each of us can do to avoid the risk, or to reduce the risk of getting these kinds of diseases."

When asked if he was saying funding for a public education campaign would not be made available he replied, "I'm not saying that at all. The Government spends hundreds of millions of dollars on these sorts of issues, but in the end, 'just say no' is probably a pretty good message to illegal drug use."

In an interview with *PM* on November 12, Australian Hepatitis Council executive officer Jack Wallace said the Government's approach would not stop the epidemic getting worse.

"There's a lot of words and not terribly much action and there doesn't seem to be any resources around to actually address the fact that hepatitis C transmissions have increased by 45 per cent over the last four years," Mr Wallace said.

"One of the things that came up in the national hepatitis C strategy was the fact that we need to develop innovative strategies. This Government does not seem willing to do that and in fact does not support the recommendations made by a whole range of experts."

■ Lisa Waller is president of the Hepatitis C Council of NSW and a member of *The Hep C Review* editorial committee.

2004

Hepatitis C in 2004: where do we stand?

By Stuart Loveday

Imagine an epidemic with almost 50,000 new infections in just three years, a highly virulent blood-borne virus which already affects more than a quarter of a million people, where estimated transmission rates increased by 45% in four years and which show no signs of slowing.

Imagine a population in which most people had no idea of the extent of the epidemic going on around them, the impact it might have on their lives, where governments and health authorities struggle to provide more than a basic range of services, and where less than 5% of those infected have ever received treatment.

Unfortunately, we're not talking about a remote region of the world miles away from us – we're talking about Australia. And that epidemic is hepatitis C.

It's not an overstatement to say that the epidemic is out of our control at present, and that our response to date has failed to rein in the spread of the virus, and failed to limit the likely future healthcare and societal costs.

We have recently seen more media attention focused on hepatitis C than would normally be the case for what a 1998 NSW parliamentary report referred to as '*The Neglected Epidemic*'. Unfortunately, the attention hasn't been positive, reflecting serious shortcomings in our response to the epidemic and those people affected by it.

While mortality rates in hepatitis C are relatively low, the sheer numbers of people infected mean that thousands of people will develop serious, life-threatening liver disease now and over the coming decades.

So what went wrong? How did we find ourselves so far behind the eight-ball? Is it that we believe a disease predominantly affecting injecting drug users is someone else's problem?

I'd suggest we think again. Clearly, all Australians with hepatitis C access the public health system for a broad range of health services. This comes at a cost; we know that there is widespread stigma and discrimination faced by people with hepatitis C. This adds to that cost.

The recent media coverage concerning the politics of hepatitis C, particularly around the attempted tabling in parliament of an embargoed Commonwealth Government review of Australia's first National Hepatitis C Strategy, will hopefully give us the impetus we need to regroup around the ideals laid out in the existing Strategy.

Australia has an enviable record in its timely, bipartisan and comprehensive public health responses to infectious diseases. Our response to HIV and AIDS was lauded around the world for its pragmatic approach – an approach which showed tangible results in terms of lower infection rates, best practice treatment and care, and a highly educated and supported healthcare workforce that works with the affected populations.

But in relation to the hepatitis C epidemic I think we're coasting, patting ourselves on the back for the effort we put into minimising the impact of HIV/AIDS in Australia.

It's time to regroup and drop the rhetoric – this time we're starting from behind and we're losing valuable time.

By all accounts, the review of the National Hepatitis C Strategy outlines succinctly where we've gone wrong, why the partnership approach isn't working as well as it should, and what we need to do to mount an effective response.

If nothing else, I hope the review clears up any debate about what needs to be done. We know what needs to be done. More words won't help, but action will.

What we need now is leadership, certainly not more reports and reviews to tell us what we need to do next. And at least in the short term, it isn't just about more money. We need decisive decision-making and we need it now.

On behalf of more than a quarter of a million Australians affected by hepatitis C, I call on the Federal Health Minister to form a taskforce to implement the findings and recommendations of last year's review of the National Hepatitis C Strategy. I call for the formation of a new national advisory body to guide the development of a second National Strategy, and for everybody involved in the recent media furore to step back and look for positive outcomes rather than political point-scoring.

In the interests of partnership we offer the services of a small and dedicated community workforce to work towards achieving a renewed impetus on hepatitis C.

If we do this, and do it soon, we may have a chance of minimising the personal, social and economic costs of this tragic failure to act.

■ Stuart Loveday is president of the Australian Hepatitis Council and executive officer of the Hepatitis C Council of NSW.

This article is a transcript from the ABC Radio program, *Perspective* broadcast on 28 August 2003: http://www.abc.net.au/rn/talks/perspective/stories/s933852.htm

Drug dependent - disal

2000

The Federal Court "Marsden" case finding suggests that addiction to a prohibited drug could constitute a "disability" and the person would be covered under the Federal Disability Discrimination Act.

2001

NSW Government changes its anti-discrimination laws to allow workplace discrimination against people with drug dependency.

September 2003

Legal action launched by Sydney man against Botany Council after being "sacked" after employer discovered he was on methadone.

November 2003

Federal government moves to amend Federal Disability Discrimination Act in order to remove dependency on illegal drugs as a "disability" and grounds for cover.

December 2003

Green and Democrat Senators pass a successful motion referring the government's proposed changes to a Senate committee inquiry.

9 February 2004

Closing date for submissions to Senate inquiry

25 March 2004

Senate committee will report back to Parliament.

Where is the Government's "Tough On Drugs" policy leading? What new changes are they planning?

The Disability Discrimination Act 1992 (DDA) protects the basic human rights of people with disabilities, preventing them from being treated unfavourably because of prejudices, stereotypes, or stigma attached to their disability.

Under the DDA as it now stands, a *"disability"* includes the *"total or partial loss of the person's bodily or mental functions"* and *"a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions, or judgement that results in disturbed behaviour."*

The Federal Government's proposal is to amend the DDA to make it lawful to discriminate against a person on the ground of that person's dependence to a prohibited drug (unless that person is undergoing a program, or receiving services, to treat the dependence).

No other group in society would be targetted in this way. The Bill would apply to users of ALL illicit drugs and would permit discrimination in all areas of life covered by the DDA, including employment, accommodation, education, club membership, sport, and access to goods, services, facilities and premises.

Our major concerns

We believe that the Bill breaches Australia's international human rights obligations. The basic principles of non-discrimination will be undermined if the rights are made conditional - ie. you are only covered under discrimination law if you have entered drug treatment (which is often not accessible anyway).

The Bill treats people differently depending on the kind of drug they use. A person dependant on alcohol may behave in a way that makes them less able to perform the functions of their job than a person dependant on cannabis, but the Bill will operate to protect the alcoholic and not the user of cannabis.

The Bill does not define *addiction*, *drug addict*, *program*, *service*, or *treatment*. It poses a number of worrying questions:

- can a person be deemed *"addicted"* despite the fact that they are not currently using?
- would a person on a waiting list for a treatment program be considered to be *"undergoing a program"*?
- would a person who has decided to go *"cold turkey"* be considered to be *"undergoing a program"*?
- who would decide these matters?
- who decides if someone is "addicted"?
- does there need to be actual evidence of illicit drug use or is suspicion enough?
- what kind of evidence is sufficient?

bled? or second class citizen?

From a harm minimisation point of view, the Bill is a step backwards. If it becomes law, many drug users may avoid services such as needle and syringe programs for fear of being identified. Being known as a drug user could lead to their losing or being denied their jobs, housing, or other services.

To avoid this, drug users may re-use needles and may be less likely to approach health services to be tested for blood-borne viruses, increasing the risk of diseases like HIV and hep C. The Bill may therefore, in fact, increase the health risk to drug users and the community in general.

The Bill will increase the extent and negative impact of stigma and discrimination. The NSW Anti-Discrimination Board report on hepatitis C discrimination found that people with hep C experience extraordinary discrimination in all aspects of their lives. This was linked to a community perception that it is acceptable to discriminate against drug users.

The Bill says that someone could not be discriminated against merely because their partner, parent, brother, sister or friend is a "drug addict." But try telling that to kids who have no roof because a parent has been kicked out of their flat or lost their job.

The amendment will clearly have a negative educational and social impact because it will reinforce stereotypes, stigmas, and prejudices attached to drug dependence by making it legal to deny drug users jobs, housing, and other services simply because they use a particular drug rather than because of their work performance or personal behaviour. Stereotypes of drug users rather than the behaviour of the individual will dictate whether they will find work or have a roof over their heads.

The notion of drug dependence as a self-inflicted harm also creates problems. Should people with disabilities or conditions caused by use of legal drugs (tobacco, alcohol) or a result of dangerous driving or hang gliding also be excluded from the anti-discrimination and human rights laws in Australia?

Drug treatment

The Bill impacts upon people depending on whether or not they are undertaking drug treatment. But drug treatment is not presently available, accessible, or appropriate for all people, particularly financially and socially disadvantaged people, or people who have an underlying mental illness.

Many drug rehabilitation and treatment centres have long waiting lists which prevent people from seeking treatment. Furthermore, research has shown what we all know from experience or intuition: treatment for drug dependence is less likely to be effective if it is involuntary, coerced, or compelled.

Safe working environment

The Government says that the Bill is necessary to keep the work and social environment safe from other people's behaviour. Don't let them pull the wool over our eyes. There is no need to change the current DDA - it doesn't protect anyone who acts unsafely at work or in public. No one in the Australian workforce or who uses public services, whether they have a disability or not, are exempt from Occupational Health & Safety requirements.

By allowing discrimination on the basis of an individual's dependence, rather than on the basis of actual risk or hardship, the Bill may lead to people concealing their dependence on drugs.

This would make it harder to identify and assess real risks in work and public spheres.

The fact that the Bill does not define key terms such as *addiction*, *drug addict*, *program*, *service* or *treatment* means that employers and organisations will in fact be very unclear about whether they are permitted to discriminate or not. The Bill is likely to generate a great deal of courtroom litigation.

Contacting your federal member of parliament

If you have an opinion on the government's proposed Bill, whether in support or against it, you should contact your federal member of parliament and your State/Territory senators.

On the internet, go to http://www.aph.gov.au/index.htm and click on "House of Representatives". Then click on "members" and "electorate list" (if you are not sure of your electorate, the House of Reps home page has a "find your electorate"button). By finding your electorate and clicking on it, you'll be given your member's contact details. His/her staff will gladly take your phone call and listen to your views.

Likewise, by visiting the "Senate" webpage and clicking on "Senators", you'll be able to find your State/Territory senators. Many of the senators have toll-free phone numbers or email addresses and all are eager to hear your views.

■ This article is based on a brochure downloadable from www.disabilitydiscrimination.info

(Also see Brian Greig's editorial, page 2.)

HEP C NSW

Your online meeting place

This March, visit the chat room to meet special guest,

Dr Greg Dore.

Wed 31 March

6pm - 8pm

In April, the special guest will be Kimberley Clarke, coordinator of the *C-een & Heard* hepatitis C speakers service.

May's special guest will be Prof Geoff Farrell.

http://hepatitisc.communityzero.com/

United Nations harm-minimisation measures

The UN is now promoting harm minimisation measures to prevent HIV and HCV infections.

Ten people are infected with HIV every minute of every day, 95 per cent of them in developing countries. The fastest growing rate of new infections is now found in eastern Europe and in central, south and south-east Asia, where HIV *[and hep C]* is being transmitted mainly through the sharing of drug-injecting equipment.

It is estimated that ten per cent of all infections result from unsafe injecting behaviour. It is also estimated that there are 12.6 million injecting drug users worldwide. In some regions, up to 90 per cent of all injecting drug users have HIV. The prevention of HIV/AIDS associated with drug use is core to the work of the United Nations Office on Drugs and Crime.

There is overwhelming scientific evidence that a comprehensive package of interventions can prevent and reverse an HIV/AIDS epidemic among injecting drug users. However, in most countries where injecting drug use is a significant route of HIV transmission, less than five per cent of all injecting drug users are reached with prevention services. Experience indicates that decisive prevention activities often start only after a significant number of injecting drug users are already HIV-infected.

The fight against HIV/AIDS requires an ongoing commitment, political will and courageous leadership at all levels. Only sustained and comprehensive approaches to prevention, care, and treatment can work. Interventions need to be accelerated with the support and involvement of people from all walks of life, including people living with HIV/AIDS.

The United Nations is playing a leading role in raising awareness and supporting global, regional and national efforts to prevent and arrest the spread of the twin epidemics of HIV/AIDS and injecting drug use. For example, the United Nations Office on Drugs and Crime (UNODC) is working on a pilot project to minimize the adverse health and social consequences among injecting drug users in Karachi, Pakistan. The project set up two drop-in centres to provide life-saving services such as a needle exchange, condoms, peer counselling and basic primary health care, including referrals for drug treatment. The centres serve approximately 1,000 people in Karachi who inject drugs.

■ UN Information Service

THE 3D PROJECT

Diagnosis, Disclosure, Discrimination and People Living With Hepatitis C

The 3D research project: diagnosis, disclosure, discrimination and people living with hepatitis C.

Back in 2001, The National Centre in HIV Social Research (NCHSR) in collaboration with the Hepatitis C Council of NSW commenced the 3D study to find out what life was like for people in NSW with hepatitis C.

A questionnaire was inserted into the March and June editions of the *Hep C Review* and readers were urged to complete and return the survey as well as volunteer to be interviewed.

The study recently concluded and a report was launched in late 2003. Copies of the report can be downloaded from the NCHSR website at www.nchsr.arts.unsw.edu.au (just go to 'Publications' then 'Drugs and Hepatitis' and click on The 3D Project).

If you are not a citizen of cyberspace, do not despair. We will be bringing you key findings from this study over the next few editions of the *Hep C Review*. Stay tuned.

■ NCHSR

Heplink: keeping health workers connected!

HepLink is a NSW statewide interagency of health care and other workers who address issues relating to hep C in their work.

It aims to..

- ***facilitate networking***
- ***provide a forum to address issues of common concern***
- ***enable workers to share information and resources***

There are two aspects to *HepLink*: face-to-face meetings and an email network. Meetings are interactive and structured around issues identified by *Heplink* members.

HepLink activities are organised by the *HepLink* steering committee, which is drawn from the membership.

HepLink meetings are held in Sydney every 3 months. In 2004 there will be some money available to fund rural and regional workers to attend.

Meeting dates for 2004 are:

Friday March 12th 10am-1pm
Friday June 4th 10am–1pm
Friday Sept 10th 10am–1pm
Friday December 10th 10am–1pm

Topics and venues will be announced closer to the date.

HepLink membership is open to any worker in NSW with an interest in hepatitis C. The group currently has more than 170 members, representing a wide range of sectors including: nursing, health promotion, social work, research, education, policy, allied health, alcohol and other drugs, needle and syringe programs, and treatment specialists.

■ For more info, please contact Sallie Cairnduff at the Hepatitis C Council of NSW or visit our website:
salliec@hepatitisc.org.au
02 9332 1853
http://www.hepatitisc.org.au/education&development_site/heplink.htm

Hi, my nan

I've been living with hep C for more than 25 years, although I've only known about it for the last 13 or so.

If you're anything like most of the health professionals I've spoken to, I think I know the first question that you want to ask. Because I know that you (and most health professionals) mean well, I'm going to answer it. Yes, I got it through injecting myself with drugs. I was in my teens in the 70s after all and we were supposed to experiment, weren't we?

I guess I had an ideal world pictured at the time, and I was trying to live in it straight away with the help of modern chemistry. However, I definitely wasn't thinking about the frailties I carried within me. I guess I thought I was better than 'them' and I would be able to 'get away with it'.

To a degree I guess I was right. I'm still here, and, when I decided to get regular work and live a sort of normal life I was able to do that. Living the straight life wasn't easy at first. Most of my friends couldn't understand why I wasn't as much fun as I used to be and I had to make myself a whole new life. But I was sick of the one I was living and really wanted to change, so I hung in.

As part of getting straight I worked in the local courts and social security as a clerk, and found out that I'm a bad clerk. Then I drove government buses for a while and that paid okay so I was able to build up some savings. After a couple of years of that I quit, bought a motorbike and toured around Australian youth hostels for six months or so.

That was great, I got a clear idea of what I wanted to do. I wanted to go to Uni. The social life seemed good, and my savings meant that I wouldn't have to suffer much as a poor student. University was fun and I finished with a BA in psychology and started working in group homes with the disabled, which is tough work.

Because I enjoyed studying I took some postgraduate psychology courses at Sydney Uni. I was working with the disabled, getting lots of fresh air and exercise, doing well in my studies and I'd met someone who's turned out to be my life partner. It was one of the best times of my life. Then I donated blood and got a call from the blood bank. A visitor from the past. I had hep C.

It was in 1990, so no one knew much about hep C. I was seeing a good GP at that time and she told me what she knew, but that wasn't much. I saw a specialist, and he told me that I had no option but to go on interferon, which was experimental at that stage.

Maybe it would have been better if he'd talked to me about waiting a bit to see how my hep C progressed. Hep C doesn't work that quickly, I wasn't urgently in need of treatment and....the treatment's not as simple as taking a couple of aspirin for a couple of days.

So I was injecting again, but this time it was to undo the damage from the first time around. The first month was great. I felt good and my liver function tests went straight to normal. What a great drug! Then the side effects started and my liver function tests went back to where they started. Rats! And that's how my treatment finished. No sustained viral response, as they say. I wasn't 'cured'.

ne is Gren

But, on the bright side, I still felt okay, and could carry on with what I wanted to do in life. I got married, did an honours year in psychology, and then went on to do a PhD in food perception. I was still being monitored by Westmead, but neither I nor Westmead was putting much effort into it, and I wasn't feeling any symptoms.

The fact that I wasn't feeling any symptoms had its good and bad points. The good was that I could live a normal life; the bad was that I didn't have to take care of myself to feel okay and I was probably damaging my liver more than I needed to by living too hard.

Above photo by Anthony Weate, courtesy of Newspix.

Doing a doctorate wasn't easy, and after I finished studying I worked for five years for a private company involved in market research, where I worked an average of about 60-65 hours a week, and up to 110 or so, while putting up with demanding clients who continually changed their minds about what they wanted to do. Sometimes out of frustration I drank more than I should have and swore a lot.

I flew around the country and occasionally overseas, ate at good restaurants and stayed in good hotels when on business. It was a glimpse of the yuppie lifestyle, but it was hard work and for my own sake I had to stop. I was always tired, and I started to feel 'not quite right' over the last year or so.

Suddenly, after working really hard and living a bit of the high life, I was unemployed. Aside from lying on the couch and watching lots of TV, I also went to doctors and had a lot of tests done. I was making up for lost time.

The tests included a biopsy.

Well, the passing of time and the high stress lifestyle have taken a bit of a toll. I've developed some fibrosis. What this means is that my liver's sustaining damage and I might be a candidate for another round of interferon. Combination therapy this time and I don't have a more than 50% chance of getting cleared on that therapy either, so I'm not that keen to give it a try just yet. On the medico's side they say that it's too expensive to give to 'someone like me' (who's not feeling that unwell). Onya guys, way to make me feel valued!

So how do I feel now? I'm still tired, even though I'm not working much. But whether it's just getting old, or due to the disease I just don't know. I know I'd be happier if I didn't have the virus, but I do have the virus so I just have to get on with things. Meanwhile I'm trying to get lots of rest, eat reasonably well, not drink much alcohol and get a bit of regular exercise. I'm also keeping my fingers crossed and barracking for the hep C medical researchers to develop a more effective therapy than what we have now.

However, *"Go the Monoclonal Antibodies"* doesn't have quite the same broad appeal as *"Go the Wallabies"*. So maybe I'll have to wait a little longer than I'd like.

C'est la vie.

■ **Gren, Sydney.**

Alcohol intake warning

Alcohol can be a real problem for many Australians. Given that the mix of alcohol and hepatitis C is linked to increased liver damage, Australians with hepatitis C should be doubly concerned.

Thirty one thousand Australians killed and 600,000 more hospitalised. That's the massive toll that's been inflicted on the nation over a decade by that cruellest of masters, the demon drink.

New research suggests that Australia has a big drinking problem, with the finding that four out of five alcoholic drinks consumed in this country will actually be putting drinkers at risk of acute harm.

NICK GRIMM: Drink more than four standard alcoholic drinks a day if you're a man, or just two if you're a woman, and you're on your way to long-term health damage.

The report is titled *Australian Alcohol Indicators*, and indications are that we simply don't have our drinking under control. It makes for, well, sobering reading. There's the disturbing finding that, collectively, Australians lost 80,000 years of life as a result of alcohol. That figure was racked up over just a decade.

Researchers from the National Drug Research Institute compiled statistics on alcohol consumption from 1990 through to 2001.

TIM STOCKWELL: At least 80 per cent of the alcohol consumed in any one year is drunk in a way which is putting the drinker's health and safety at risk.

NICK GRIMM: Professor Tim Stockwell is the Director of the National Drug Research Institute.

TIM STOCKWELL: It is quite clear that we still have a massive health and social problem with alcohol. The estimate is of 31,000 deaths over 10 years up to 2001, and almost 600,000 hospital episodes caused by alcohol consumption.

NICK GRIMM: Okay, what sort of quantities are we talking about on an individual level; what sort of quantities would be causing damage like this to a person?

TIM STOCKWELL: We've used a reference point from the National Health and Medical Research Council, the Australian alcohol guidelines, so we're talking about an average of more than four drinks a day for men and two drinks for women.

NICK GRIMM: So more than four standard drinks a day will be putting a person into this danger zone?

TIM STOCKWELL: Absolutely, yes. I mean, the other good news is that within those limits, particularly light levels of drinking (around one to two drinks a day for men and about one drink a day for women), it's believed that that protects people from heart disease, and we estimate that in any year, there's as many as 6,000 lives saved through light drinking.

NICK GRIMM: So, while many of us are dying sooner as a result of alcohol abuse, there's also a significant number who can thank a daily tipple for a longer, healthier life.

Put into statistical language, those sensible drinkers will collectively enjoy an extra 61,000 years of life.

■ This is an abridged version of a transcript of the ABC current affairs radio program, *AM,* 17 November 2003: www.abc.net.au/am/content/2003/s990469.htm

For guidelines on alcohol consumption and hepatitis C, please see www.alcoholguidelines.gov.au/groups.htm#guideline4

Also see Ed 35 for various articles on hepatitis C and alcohol.

Reflections on C talk

The C-talking support group has been good to compare notes and share stories with others. I wished it existed when I was starting treatment because I was confused by the contradictory and misguiding information around.

In particular, there was a lot of information about the old interferon (3x weekly) but little on the new pegylated interferon (1x weekly).

What I had read about the side-effects of the old interferon wasn't even close to what I experienced with the new version. While I have had my share of side-effects, they haven't been to the extent I was expecting after reading about the old stuff.

The support group has been a good space to listen to others' experiences and to share my own. It is also worthwhile to hear how others are coping with their side-effects and what they do to pamper and look after themselves. Most of us are at different stages of treatment and it is encouraging to see someone close to the end while, at the same time, supporting those who are about to, or have just, started.

Each session has had a speaker from St Vincent's hospital to talk about hep-related issues. So far, there has been someone from the social work/counselling, drug and alcohol and the pharmacy.

■ Anon

C Talking at St Vincents

- an inner city support group

The fact that something more was needed became clear when talking to patients about their interferon and ribavirin related side-effects. People were thirsty to know how others were coping and managing their symptoms. Above all, they were seeking reassurance that they were not alone, and that others, too, were experiencing these sometimes difficult times.

As professionals, we can advise and provide support to the best of our knowledge but in cases like these, the most qualified person is the one with first hand knowledge: the patient! And so, our treatment support group was born.

The venture, which has now taken the name of C-talk (named personally by one of the members), takes place on the first Tuesday of every month, at St Vincent's Public Hospital, Darlinghurst, Sydney.

It is patient driven, meaning, we rely on feedback from the members on how to shape and direct the group from those who need it most. We have a guest speaker from one of our many support services; ie. social work, dietician, drug and alcohol, pharmacy, etc, to enlighten us on how they can assist people through their treatment and we all share the ultimate goal of people achieving a sustained viral response.

We are a friendly and informal group who love to share a joke or experience. So, although being a serious matter, we can still find time to laugh and jolly each other along. It's a great opportunity to discover people who are walking in the same shoes.

Partners and friends are welcome, as we appreciate this life experience can greatly affect them too.

A light supper is provided and we are accessible by bus or train and hospital parking is available.

So why not come along and learn from people's personal experiences. Together, we will all gain a richer education in managing and coping with interferon and ribavirin therapy.

■ For further information, please contact Zoë Potgieter (CNC, Viral Hepatitis).
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Can interferon prolong life?

Should people who don't achieve sustained response be provided with low dose interferon as a long-term maintenance therapy to help prevent liver failure or liver cancer?

In the past few years, the prevalence of liver cancer (hepatocellular carcinoma, or HCC) has increased in western countries and currently cirrhosis related to the hepatitis C virus (HCV) is the most common cause of liver transplantation worldwide.

Studies projecting future complications of chronic hepatitis C, using mathematical models, are not optimistic. A substantial number of currently asymptomatic patients with HCV will progress to cirrhosis and HCC in the coming years, and it is estimated that the number of liver-related deaths will increase by 180%.

Antiviral therapy for patients with chronic hepatitis C has the final objective of decreasing the mortality of infected patients by preventing HCC and decompensation of cirrhosis. Given the difficulties of putting these objectives into practice, we use the sustained virologic response as a parameter to measure these goals.

Sustained response is defined as the clearance of virus, which means HCV remains undetectable by sensitive methods six months after the end of treatment.

Follow-up studies have shown that response continues in the majority of people and the progression of liver damage is stopped. It has been shown that liver fibrosis diminishes when the inflammatory activity disappears; this probably is due to the antifibrogenic [protective] effect of interferon.

It is important to note that even in patients without a sustained response, liver condition may improve by stopping the progression of fibrosis.

In this setting, there are some difficult questions:

- Can antiviral therapy prevent the development of liver cancer?
- Does antiviral therapy prolong the survival of treated patients?
- Might therapy be beneficial in nonresponders?

The still unanswered question is whether interferon therapy can be beneficial in nonresponders.

Different studies show that patients who achieve a biochemical response with normalisation of alanine aminotransferase levels but without a virological response seem to have a lower incidence of liver cancer during follow-up evaluation and this could be related to the suppression of fibrosis progression by interferon.

If this assumption is correct, the current rule of discontinuation of therapy in nonresponders at week 12 should be revised to provide long term benefit for a higher number of people. Whether longterm maintenance therapy with pegylated interferon could be of additional benefit in clinical terms, due to its antifibrogenic effect, still needs to be clarified.

The answer will probably be found when the three current studies (HALT, COPILOT, and EPIC) with interferon maintenance are completed.

■ This much-abridged article by by Dr Rafael Esteban, Barcelona, Spain, was originally an editorial in the August 2003 issue of *Hepatology*.

The full copy is available via hivandhepatitis.com: www.hivandhepatitis.com/hep_c/news/100603_b.html

HALT:
http://www.liverfoundation.org/db/articles/1024

COPILOT:
http://www.hepcassoc.org/news/article54.html