The Hep C Review

September 1995 No. 12

CHINESE HEP C SPECIALIST VISITS SYDNEY

A visiting Chinese hepatitis specialist, Professor Chen Jian-Jie, recently visited the Council for meetings with Australian hepatitis C specialists and natural therapists.

Professor Chen Jian-Jie is one of China's leading clinical, academic and scientific experts on the use of traditional Chinese medicine (TCM) for treatment of hepatitis.

Seated L-R are Prof Batey, Prof Chen & Stuart Loveday. Standing L-R are Christine Berle, Gary Seifert, KC Tang & Tony Xie.

At present he holds the position of Deputy Chief Physician at the Shu Guang Hospital, Shanghai University of TCM, where he specialises in the treatment of hepatitis C & B.

He is also a lecturer and a Phd supervisor at the Shanghai University of TCM.

Also present at the Hepatitis C Council sponsored meeting was Professor Bob Batey, of the John Hunter Hospital, Newcastle, and member of the recent National Health & Medical Research Council Hepatitis C Taskforce.

Other people present included: Mr Tony Xie, Project Scientist, University of NSW; Ms Christine Berle, Acupuncture Branch Chair, Australian Natural Therapists Association; Mr Gary Seifert, Principal of Sydney College of TCM; Mr KC Tang, hon Visiting Fellow, School of Community Medicine, University of NSW; Stuart Loveday & Paul Harvey, both of the Hepatitis C Council of NSW.

The purpose of the meeting was four fold: to get from Prof Chen an overview of Chinese TCM work

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VIC gets hepatitis C info hotline

VICTORIAN GPs can now get information and advice on hepatitis C via a telephone enquiries line set up by the Victorian Health Department.

The inquiries line is part of Victorias hepatitis C strategy, launched in July by Health Minister Marie Tehan.

She said the strategy was designed to educate health professionals and at-risk groups about the disease. The number of notified cases nearly doubled in Victoria between 1991 & 1994.

"The Victorian strategy will standardise the diagnosis and management of hepatitis C and also introduce a range of measures to reduce the transmission of the infection in the community," Mrs Tehan said in a media release.

Victoria can take pride in its leading role in initiating a nationally cordinated approach to the problem."

The media release said GPs could telephone the hepatitis C educator at the gastroenterology department of St Vincent's Hospital, Melbourne, for general information and management advice.

The strategy booklet said the government planned to improve hepatitis C surveillance, peer support services for hepatitis C sufferers and patient information brochures.

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with hepatitis C patients; to give an outline of what is happening here in Australia with TCM treatment of hepatitis C; to discuss the John Hunter Hospital, Chinese herbal treatment trial being run by Prof Batey; and to consider what action the Hepatitis C Council should take in regard to informing people of TCM treatment.

It was noted that TCM work in Australia was developing well and that Prof's Batey and Chen would liaise on an ongoing basis to fully determine the worth and appropriateness of TCM as a viable treatment for people with hepatitis C infection.

It was also noted that formal results of the first stage of the John Hunter trial would not be known for two or three months. With these trials, the clinician (Prof Batey) does not know himself which patients are receiving the TCM treatment and which are receiving the 'dummy' treatment, until the trial is completed and the results analysed.

The possibility of a second stage of the trial was discussed. This would involve the individual treatment of patients, as opposed to the standardised treatment given to all current trial patients. The second stage is being welcomed by TCM practitioners because it more closely reflects the reality of TCM patient treatment.

In China, herbs are used extensively to treat hepatitis. Acupuncture and herbs are also used widely to treat a whole range of disease conditions.

Prof Chen said that in China, excellent results are achieved following traditional diagnosis (tongue and pulse) of an individual, followed by application of a range of natural herbs.

Simultaneous monitoring of liver function test results indicates that

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EDITORIAL

SICK PEOPLE MUST COME BEFORE A SICK ECONOMY

A guest editorial by Marianne Robinson.

Overnight, medical treatment has become a public issue rather than a private one. Doctors and patients appear to be losing the battle for control over treatment decisions. As demands on the healthcare system increase, the community is being told that the need of the individual must be balanced against the capacity of all to pay. This battle for the shrinking medical dollar is even being fought in the courtroom.

The issues in this debate will impact on each of us. Therefore we have a right to know about the issues and play a part in the determination of the relevant policies. This is not an area in which decisions should be made by stealth. Nor should it be left to a limited number of individuals making ad hoc decisions.

The risks posed to our communities by the wrong choices in this area are great and they should be discussed openly before the court battles begin.

Do we want economists to hijack medicine or should the community be entitled to express an opinion about who controls medical decisions? As individuals, we have limited means of expressing our views. We can vote or we can take our case to court.

The use of the discrimination laws as a basis for deciding these issues is inappropriate, but they may well become the focus for bringing the issues to the public's notice.

The Australian discrimination laws make it unlawful to treat someone less favourably on the basis of impairment. Although the laws have existed for some time, there have been relatively few cases brought. Those now coming to an end are cases with thought-provoking consequences to suppliers of goods and services.

There are reports of that the Human Rights Commission is receiving more than 50 complaints a month under the heading of Disability Discrimination.

One recent case involved a 32 year-old welfare worker, who with the support of others, successfully delayed the tender for 275 new STA buses until it was agreed before the Human Rights and Equal Opportunity Commission that the buses be fitted with wheelchair access.

Cases of discrimination are not always as obvious as this one. Discrimination can be more subtle because it is unlawful to deny goods or services, or to perform the services on less favourable terms because of the personal characteristics covered by the discrimination laws. The term "services" includes services provided a public authority such as a hospital.

It is possible that this could be the mechanism to bring to public attention, the issues in the health debate. It is unlikely though, that this option would bring together the appropriate groups whose input is needed to fully explore the issues.

At a time when hospitals are facing increasing expenditure cuts and the Federal government is examining the pharmaceutical budget, there is a

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The Hepatitis C Council of NSW

is an independent, community-based, non-profit organisation providing information and support to people affected by the hepatitis C virus. We are primarily funded by NSW Health.

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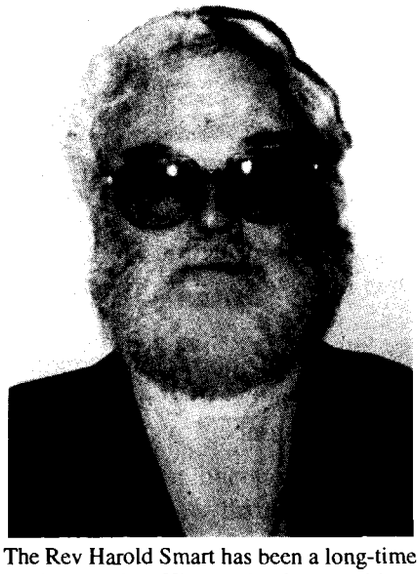
Getting to know your Council



The Rev Harold Smart has been a long-time active member. His ongoing letter-writing campaign has greatly assisted the Council.

'FROM THE WIRE' - NEWS FROM OVERSEAS

HEP C RATES ON THE RISE

In the alphabet soup of hepatitis causing viruses, HCV is the most commonly diagnosed culprit in liver transplant cases, yet hepatitis C is the one nobody talks about, said Dr Teresa Wright, chief of gastroenterology at the San Francisco, Veterans Administration Hospital.

Some 4 million people in the United States are now HCV infected. This compares to 1.5 million thought to be infected with HIV, the virus that causes AIDS.

Wright noted that fully 10% of the patients admitted at the hospital, for whatever reason, carry HCV in their blood. At least 80% of those who contract the virus develop a chronic infection, compared with fewer than 10% for the better known hepatitis B virus.

The medical tragedy will translate into a multi-billion dollar market for whoever arrives first with a vaccine or truly effective cure.

NEW TREATMENTS?

It is estimated by the Centres for Disease Control (CDC), Atlanta, that between 2.5 and 5 million Americans have chronic HCV infection. It is further estimated that there are 400 million people infected, world-wide.

There is no known cure for hepatitis C. Alpha Interferon is only marginally effective against HCV, and yet $500 million worth of the drug is sold annually in Japan alone for hepatitis C and B treatment.

A treatment for HCV represents one of the largest pharmaceutical market opportunities in the world.

MICKEY STRIKES 2

Hepatitis C virus, a microbe even more elusive than the virus that causes AIDS, is one of the more significant causes of liver disease - a so called silent killer that afflicts an estimated 150,000 Americans every year.

Baseball great Mickey Mantle's drinking habits got a lot more attention, but it was alcohol in combination with HCV that wiped out his liver and required a life-saving operation.

Were it not for the media attention on the occasional celebrity with liver disease (they include singer Naomi Judd, the late TV news-anchor Frank Reynolds and actors Larry Hagman and Jim Nabors), hepatitis C would be even less of a public health issue than it currently is.

CANADIANS START TO WISE-UP

A cooperative development involving The Canadian Red Cross Society, Health Canada, the Canadian Liver Foundation and the private sector has led to a National Hepatitis C Education Program.

The program will involve hepatitis C seminars in Canadian cities across the country throughout 1995. Such seminars are aimed at physicians, people affected by HCV and the general public.

Doctors and the public want to know more, it was claimed by Mortimer Bistrisky, President of the Canadian Liver Foundation.

He stated the program is responding to a clearly identified demand for thorough, accurate and up-to-date information about the viral condition.

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SICK PEOPLE MUST COME BEFORE A SICK ECONOMY

very real concern about how to balance the rights of the individual needing treatment against the financial ability of the community to meet costs.

Unless the questions are asked and discussed now, the community runs the risk that the battles will take place in the law courts. Questions of policy on morality and finances are not best argued in court, nor should they be.

A timely reminder comes from Philip Howard, the author of *The Death of Common Sense - How Law is Suffocating America:*

"Law should articulate goals, ward subsidies, allocate presumptions and provide mechanisms for resolving disagreements but law should almost never provide the final answer. Life is too complex. Our public goals are too complex. Hard rules make sense only when protocol is more important than getting something done."

As a community, we need to ask whether we want to surrender the health of any one individual in order to achieve a healthy economy. We deserve that choice because medical treatment affects us, not economic models.

When you go to the doctor, think about who else is sharing the consultation. Do you want the decision for your treatment to be a medical one or an economic one? Should you have a choice?

Marianne Robinson is the executive counsellor for the Australian Institute of Risk Management. This article was taken, with permission of writer and publisher, from the 'Opinion' page of the Sydney Morning Herald - Thursday 24 August 1995.

LETTERS TO THE EDITOR

To the Editor

Thank you for your service. It was a great relief to know that Hep C was known at a grand scale as I thought it would be quite uncommon.

Your reviews are wonderful as it is a great outlet for us to express our relief or turmoil in discovering that we are HCV positive.

This letter is for my children Aaron, Sue-mi and Jacob who bring much joy and love into my life, and for my great dad who has loved and supported me through all the bad times and the good.

Yours faithfully, Ms T.H.

To the Editor

I received *Hep C Review* No. 11 yesterday. I am hepatitis C positive and will be seeing a gastroenterologist next month to arrange a liver biopsy.

I thank you for your help in obtaining up to date information about this disease. I tried to obtain detailed information from the local GPs about hepatitis C but they didn't have any. I got some information from a friend and passed it on to the local doctors. Its ironic that a patient has to give the doctor information about a disease.

As you can imagine, I appreciate the help you have given me in learning about this disease.

I am cheesed off about the misinformation given about the risk of cirrhosis as recently as last year. Is it true that recent information suggests that the incidence of severe liver damage is much lower than 50%?

Yours gratefully, Ms K.A.

(It is estimated that 20% of hep C infected people will develop cirrhosis after 20-25 yrs. It is also estimated that 50-60% of hep C infected people will develop hep C symptoms - Ed.)

To the Editor

Last year you reported in the Hep C Review that there had been a NSW Taskforce that was going to look into hepatitis C.

I haven't heard anything about this taskforce for ages. Did anything come of it?

Regards, Mr F.McN.

(The taskforce met several times late last year. Early this year, an ensuing report was put to the Director General of NSW Health. No further government action seems to have been taken.)

To the Editor

I've recently been diagnosed as HCV positive and I'm thinking about joining the Council as a concessional member.

I read your information pack which was good but found parts of it a little hard to understand. I want to find out as much as I can about hepatitis C and other news about it. I like your newsletter because of this.

I'm writing though because I think your phone service could be improved.

When I first got through to the freecall number, a long recorded message gave me a list of other numbers to ring.

I got the information I wanted but had to make some pretty expensive calls to get it.

What's the point of having a freecall number if all it does is give me other numbers to call that I have to pay for?

Yours faithfully Mr R.G.

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LETTERS TO THE ED.

Dear Stuart and Colleagues,

I hope you can help me. For some time I have not socialised much with other people for fear of discrimination because of my hep C status.

I would like to establish a procedure for people like me who wish to contact others for friendship and possible relationships.

I have seen similar things with other newsletters and have seen enquiries in past issues of the Hep C Review.

Thank you all, Mr A.F.

Dear Madam/Sir,

It seems the NSW government does not feel that it is necessary to increase the funding of the Hepatitis C Council.

I was appalled and later outraged when I discovered that the Hepatitis C Council receives a measly $86,000 a year from the NSW Health Department, and no funding whatsoever from the Federal government.

It seems that funding is not likely to increase until hepatitis C sufferers and their friends and families, and other concerned citizens take to the streets to draw attention to the inadequate funding levels.

How on earth is the community going to become aware of HCV with this level of funding? How effective can the Hepatitis C Council be until action is taken?

We must demand extra funding so that support groups can be established. We must demand extra funding so that professional staff can be employed to assess and effectively meet the needs of sufferers and their families.

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EDUCATION (FOR) PREVENTION?

A report by Stuart Loveday on the Australian Health Ministers Advisory Council (AHMAC) Education / Prevention Reference Working Group.

We reported in your last *Hep C Review* (no 11, June 1995) that the Federal Department of Human Services and Health had committed $3.8m over two years to fund monitoring, surveillance and education for the prevention, care and support for people with hepatitis C. It was noted that none of this money would go to community organisations. Hepatitis C councils, foundations and support groups across Australia who are involved in providing information and support have to rely on the grants each of the states and territories may make to them.

Seated L-R are Timothy, Helen, Jane and Stuart. Standing L-R are Norm, Stephen, & Patricia.

The Education and Prevention Reference Working Group is the body that will make recommendations to AHMAC about how best to allocate this limited funding.

At a meeting hosted by the Hepatitis C Council of NSW on 22 June, people in this state who have an interest in the implementation of the Commonwealth's hepatitis C National Action Plan met to review progress and advise on priorities for spending this limited amount of money.

Present at the meeting were Timothy Moore (NSW Users & AIDS Association), Ross O'Donoghue and Helen Taylor (NSW Health), Jane Freemantle (SA Health), Patricia McLaughlin and Norm Booker (Centre for Education & Information on Drugs & Alcohol) and Stephen Taylor (Prison AIDS Project).

At the meeting, we learned that there was no support from the commonwealth or other state governments for NSW's proposal for a state/commonwealth cost shared arrangement for hepatitis C although such cost shared arrangements have worked well for the funding of HIV clinical services and community groups.

We must continue to lobby for such a funding arrangement. It is the most effective way of achieving workable levels of funding that would allow the best response to unmet needs faced by people with hepatitis C.

Prevention of HCV transmission, who to target?

The vast majority of new HCV transmissions are taking place where people who are currently

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RURAL ISSUES - IN ORANGE & HCV+

A report by Phil Mercieca - from Orange, NSW

In regard to discrmination, the level of ignorance in country NSW allows for ridiculous ideas to flourish such as the spreading of HCV by drinking from beer glasses in hotels.

This situation is made much worse when misinformed General Practitioners are bought into the equation. The stigma associated with hepatitis C seems to be fuelled when doctors can't set the record straight.

Not many people will come forward regarding their HCV status in fear of being ostracised from social activities.

For example, being closely associated with the Orange Hepatitis C Support Group, it is well known that I have HCV. Recently my two children were told by one of our neighbours that they were not allowed to play with their children. No real reason was given.

What would you say to a four or six year old?

It was very difficult to explain to a little girl that she could not play with the same young friends she has played with all her life.

Another example of the ignorance and stigmatisation we face here in country NSW, was when my six year old son asked, out of nowhere, "what is AIDS, Dad?". I was quite surprised by the question and asked him why he asked. He replied that he was told by another neighbour's child that I had AIDS. I then had to explain what AIDS was and that I did not have it.

Medical treatment in regard to HCV is quite depressing - to say the least.

Firstly, there is too much misinformation within the medical profession. It often takes some time to find a GP who is up to date on hepatitis C. If then a specialist consultation is needed, a wait of several months is on the cards.

All along the track, hep C treatment is a waiting game. If there was plenty of information, this would not be a problem. Because of the widespread ignorance, the waiting game is unnecessarily traumatic.

In the case of people accepted for Interferon treatment, many country people can not get it locally so many have to travel to Sydney every eight weeks just to pick up the medication. I find the trip there and back (8 hrs) very tiring. It angers me that I go all this distance for something that I should be able to get locally in twenty minutes.

In my contact with medical services, little is ever pointed out in regards to services such as social workers and dieticians etc. This increased my feelings of isolation in the initial period of shock after being first diagnosed. I am sure many people with hepatitis C will relate to this situation.

Where I live, we do not have local phone counsellors. When we ring the freephone 1800 number, we get all these STD numbers to ring. The first time I rang one of these numbers it cost me over $30 so once I found out how expensive it was, I had to think twice before ringing anyone else for help. Now, I don't use the service because of how much it costs.

I have been told that Interferon will be available locally soon, so that will address some of my above concerns. I hope that this news is true as I have lost much faith in our health services, both state and federal.

In regard to the stigmatisation my family and I face, what is going to happen? How long do we have to wait for public education campaigns that will make life a bit more bearable out here in the country?

I hope the Hep C Council can help address the problems we face out here, because if the Council can't help address these social problems, I don't know how things are going to change.

Phil Mercieca
Orange Hepatitis C Support Group

IN RESPONSE

Phil, the Orange Base Hospital has begun treating with interferon. This will help address the problems local people have in accessing the drug. Extra funding will enable us to improve our telephone info line.

Your other concerns are not so easily addressed.

Recommendations of both the National Action Plan and the NSW Hepatitis C Taskforce directly address many of the problems associated with poor treatment and clinical management, lack of information and community support, and HCV-related stigmatisation. But these recommendations will be costly to implement (copies of the National Action Plan can be obtained from the Council). When it comes to funding such recommendations, both the federal and state governments are keeping the purse strings pretty tightly closed.

While acknowledging and welcoming Dr Andrew Refshauge's clearly stated committment to addressing the HCV epidemic (*The Hep C Review*, No 11), the current situation is that governments seem reluctant to fund the action plans they have commisioned. Can anyone suggest ways of making this happen? **Ed.**

DRUG LAW & POLICY - THEIR EFFECT ON HCV

Are Australia's current policies and attitudes towards drug use hindering the fight against ongoing spread of hepatitis C (HCV), and affecting access to assistance for people with HCV?

- a report by John MacKenzie.

Health experts have recognised that an appropriate response to HCV requires broad recognition that blood borne viral infection among people who are injecting drugs is an important public health issue.

Despite this clearly defined objective, Australia's response to the hepatitis C epidemic thus far has been marred by inadequate funding and by a marked lack of assistance for people already infected. It is apparent that those affected by HCV or at risk of infection, are being short changed.

There are many factors derailing a proper public health response. Perhaps the most fundamental is the widespread disapproval of the manner in which most HCV transmissions occur ie. sharing of injecting drug equipment. Further, the hawkish stance of governments and medical and legal authorities towards drug use has ensured little empathy for people affected by blood borne diseases.

As a result, people who inject drugs are one of the most marginalised communities in Australia and are often denied access to the health services that most people take for granted. For instance, injectors are currently excluded from Section 100 Inferferon treatment on the basis that they are 'notoriously unreliable', likely to become reinfected and thus would waste allocated funds. No mention has been made as to other types of drug use as grounds for exclusion.

Since exclusion for treatment is not based on toxicologic grounds, such discrimination is clearly a result of misinformed generalisations about people who inject drugs.

PRISONERS ARE DENIED ACCESS TO MANY OF THE RISK REDUCTION PRACTICES MADE FREELY AVAILABLE TO THE WIDER COMMUNITY

The widespread use of needle and syringe exchanges, where such services are available, is a good indicator that current injectors are increasingly aware of some transmission dangers and are willing to participate in risk reduction strategies. More information and needle exchange services can only improve injecting technique and reduce the spread of HCV.

This misinformed treatment of injectors is clearly unjust. Blame would be more appropriately placed if aimed at the lack of bureaucratic support for education, needle exchange and drug policy reform.

The need for drug law reform.

Needle and syringe exchange programs (NSEP) are now widely regarded as a practical means for reducing the spread of blood borne infections. Their implementation

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MPS' PIGGYBACK PAY BOOM

Australian politicians have outstripped average wage earners by securing pay increases totalling more than 16% over two and a half years. By piggybacking on the Federal Government's public sector pay negotiations, Federal MPs have been able to get these substantial increases.

Most State parliaments peg their benchmark salaries slightly below the Federal rate - in NSW it is a nominal $500 a year - ensuring that State MPs also benefit from the system.

The Reserve Bank has said that wages growth should average no more than 5% if inflation is to be contained within the target of 2-3%.

The politicians have achieved their pay rises without demonstrating any increase in productivity, despite this being an essential element of the enterprise bargaining system.

Increases are now staggered, avoiding the controversy which arose over whenever the Remuneration Tribunal, which previously had jurisdiction over MPs' wages, tried to address anomalies by recommending big lump-sum adjustments.

In July 1990, a Federal backbencher's salary was $58,300. By the end of next year, it will be close to $82,000 - an increase of more than 40%.

(Abridged from Michael Millett's article in the Sydney Morning Herald, 24/8/95)

[The Hepatitis C Council of NSW receives approximately $86,000 a year in financial assistance from the NSW Government to run a state-wide organisation that delivers services to the thousands of NSW people affected by HCV]

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LETTERS TO THE ED.

And we must demand extra funding so that community awareness can be raised and correct information disseminated.

A staff of three part timers, functioning on a grant of $86,000 is outrageous considering that the virus directly affects some 50,000 NSW people. Nothing will change until we make it change.

Yours faithfully, Ms L.O.

To the Editor

I would like to congratulate the Council on the excellent quality of Winter Edition (No. 11) of The Hep C Review. It is informative as well as keeping pressure on those responsible for decision making by reasoned presentation of the facts.

Best wishes, Prof G Farrell

To the Editor,

My partner of twenty three years recently passed on. Of course, his death was traumatic but it was inevitable.

The care and treatment he received in the final stages of his illness was very good and I owe thanks to his specialist and the unit counsellor.

I am a little concerned though because on his death certificate it did not say he died of hepatitis C. Our specialist said there was no specific coding for hepatitis C on death certificates.

Does this mean the government does not want it known how many people are going to die from hepatitis C? Does it want to keep everything quiet? If my husband's death can lead to benefits, then I hope my letter fixes this.

Sincerely yours, Mrs D.F.

DRUG LAW & POLICY - THE EFFECT ON HCV

(Continued from page 7)

and operation have been aided by legislative amendments to the *Drug Misuse and Trafficking Act* 1985. This means it is now legal to possess clean injecting equipment, and carry out the safe disposal of used equipment.

State laws relating to the operation of needle & syringe programs remain puzzlingly inconsistent. Both the people who administer the programs and the clients continue to fear harassment and prosecution from the police.

Standardisation of laws affecting needle exhange programs would improve implementation of risk reduction strategies and thus secure a more effective response to HCV.

Another anomaly is that drug use remains illegal in Australia. While the ACT is cautiously considering some degree of decriminalisation for heroin use, other state governments are tied to a 'get tough on crime' stance and are not inclined to consider drug law reform. In NSW, custodial sentences remain a common option when judges deliver sentence.

New research, involving people entering Victorian prisons, reveals that 46% have a history of injecting drug use and that 39% of all prisoners tested were hepatitis C positive. Approximately 85% of the women, and 64% of the men who tested positive, declared a history of injecting drug use (1). Indications are that a similar, if not worse situation exists in NSW prisons.

Prisoners are denied access to many of the risk reduction practices made freely available to the wider community. That this denial occurs despite the clearly identified need to implement risk reduction strategies gives grave cause for alarm. We seriously need to question the health implications involved in the prison environment.

Legalising of personal drug use and the introduction of other such steps to reduce the number of people who are sent to prison need to be considered.

Prohibition has proved to be an expensive, resource draining mess. Further still, as shown so clearly in the current NSW royal commission into police corruption, prohibition provides a fertile environment for corrupt activity.

The hepatitis C epidemic demands an urgent re-assessment of current policies. If we are to work towards a healthier community and a less corrupt society, we must push for reform.

(1) Crofts, N. et al. **Spread of blood borne viruses among Australian prison entrants** BMJ 1995; 310 285.

Further reading:

Wodak, A. & Crofts, N. **HIV revisited: preventing the spread of blood borne viruses among injecting drug users** *Aust. J. Public Health* 1994; Vol 18 No 3 239.

van Beek, I. et al. **Risk factors for hepatitis C infection among injecting drug users in Sydney** *Genitourinary Med. J.* 1994; 70: 321-324.

van Beek, I. **Hepatitis C - the new challenge** *Nat. AIDS Bulletin* Mar/April 1995; Vol 9 No 2.

Wodak, A. **Responding to the next epidemic** *Nat. AIDS Bulletin* Mar/April 1995; Vol 9 No 2.

Burrows, D. **Australian drug laws (where did they come from)** *Nat. AIDS Bulletin* Mar/April 1995; Vol 9 No 2.

Redfern Legal Centre Drug Law Reform Project. **Harm Reduction Model** May 1995.

[The issue of drug law reform needs to be widely debated within public forums. Similarly the situation within NSW prisons needs examining. If you have a view or any comments, write a letter to the Editor, or consider doing an article for our next edition - Ed.]

RURAL ISSUES - HCV+ AND ON THE BORDER

A report by 'Jenny' - from Albury, NSW.

I moved from Sydney to Albury in the early part of last year after a decade of working in refuges and halfway houses, and occasionally indulging in moderately risky activities. My then 'burnout' brought me to a point where I considered a life-style assessment was necessary. I was suffering from a bewildering array of symptoms which extended from the physical to the emotional to the psychological.

After what I considered to be an appropriate amount of time adjusting to the new environment and eliminating the majority of stressful elements associated with my 'old' lifestyle, I became increasingly aware of a set of symptoms which appeared to be unaffected by the changes.

By now I had developed an almost forensic attitude towards establishing causal links with symptoms and decided it was time to make contact with the local medical fraternity. After a barrage of tests, the verdict and sentence was handed down: "You're HCV positive, so practice safe sex and be careful with blood".

At least now I had a label which seemed to go some way towards explaining those inexplicable symptoms.

It took a little while for the knowledge to sink in, and then a realisation began to grow that I didn't really know anything about this label that I'd acquired.

I went looking for more info. At that time, the only information was scant and superficial and didn't go anyway towards enlightening me about the the way that I could manage the symptoms and develop a more satisfying lifestyle.

I contacted Albury Community Health after I'd participated in a local health programme, where I had fortunately met two workers who were considering setting up a local support group. I somewhat enthusiastically signed up and began what has become an ongoing involvement.

WE URGENTLY NEED HEALTHCARE WORKERS .. TO DEVELOP EFFECTIVE ONGOING SERVICES

The idea of meeting similar people, exchanging experience and information, and developing support structures appealed to me. Call me naive if you like but what I considered to be a pretty straight forward process turned out to be nothing short of an ordeal.

The nature of this disease, the rural context and the logistical problems associated with the local cross-border liaisons (Albury, NSW & Wodonga, VIC) conspired to create numerous obstacles.

The initial members of the group had previously consulted local community health staff on both sides of the border. These people had been receiving one on one support and in profile, were enthusiastic to form the core of a support group. With the aid of some health-care workers interested in the longer-term potential for a local support group, we hoped to be able to consolidate ourselves as a group and move towards autonomy.

We certainly increased our resource base by plugging into the best of available health facilities in both Sydney and Melbourne, but the personality types involved bought their fair share of interpersonal problems and the wider community exacerbated those problems and created levels of discouragement.

In summary, these local factors included:

- group members were experiencing multi levels of discrimination;
- group members held a positive attitude to injecting drug use, but unfortunately this wasn't the case with professional members or potential new members;
- group members often had different expectations about the level and nature of support they required or were able to offer others;

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NEW INFO PACKS ON THE WAY

A revised hepatitis C information booklet is currently being developed by the Council and will be hitting the streets soon. The booklet will replace the existing Hepatitis C Information Pack that all members recieve when they join.

A new hepatitis C brochure is also being currently developed. The one-page, two fold brochure has been produced in response to the lack of free information available for public distribution.

Focus testing of the booklet and brochure has involved a wide range of individuals and organisations. The information provided will be up to date and laid out in an easy to read format.

Both products have been through a first and second draft stage and are expected to be circulated to all Council members (free of charge) within 6 weeks.

INTERFERON - WHERE CAN I GET IT?

Interferon is a drug treatment that has been available for hepatitis C for over three years through drug evaluation trials.

This form of treatment is the only form of drug treatment currently recognised by health authorities. Studies are currently being undertaken on Chinese herbal treatments that could also provide positive results for hepatitis C.

Late last year, the Commonwealth government approved access to Interferon through a special scheme - the Section 100 Highly Specialised Drugs Program.

To access the drug through this program, patients must meet several criteria. These have recently been amended to include people under 18 years of age.

Patient eligibility criteria:

1 chronic hepatitis proven by liver biopsy (except patients with blood clotting problems);

2 one positive antibody test result, then a second test repeated between 4-6 months later;

3 liver function tests (with ALT readings 1.5 times normal upper limit) done three times over 6 month period;

4 absence of cirrhosis or other serious liver damage;

5 absence of HIV infection;

6 for women - not currently breastfeeding nor any chance of pregnancy while under treatment;

7 no history of significant psychiatric problems;

8 must be able to attend regularly for treatment & follow-up;

9 alcohol use of no more than seven standard drinks a week;

10 no history of injecting drug use in the previous 12 months, unless currently drug free and stabilised on methadone program for 6 months.

NB: The course of treatment involves 3 million units injected three times a week, and lasts for 6 months. If there is no normalisation of ALT readings after 3 months, the treatment will cease.

Treatment Centres:

Sometimes there are reasons why authorised treatment centres cannot treat with Interferon. The NHMRC views Interferon as 'a potentially hazardous drug with possible serious side effects' and a drug that must be monitored closely.

Treatment centres must have adequately trained staff, ideally having participated in the recent drug evaluation trials (AUSHEP01 or AUSHEP02).

There are minimum facilities that treatment centres should have before they treat with the drug. These include:

1 a nurse educator / counsellor for patients;

2 24 access to medical advice for patients;

3 an established outpatient liver clinic;

4 facilities to perform safe liver biopsy.

In rural and remote areas, State governments may wish to designate a hospital as a treatment centre for hepatitis C, provided that arrangements are made to ensure that first rate patient care and monitoring are maintained, and that reporting to the central database is maintained.

As at May 1995, the authorised treating hospitals in NSW are:

	Centre	Area	Treating?
1	Westmead	Sydney	Yes
2	Concord	Sydney	Yes
3	Royal North Shore	Sydney	Yes
4	R.P.A.	Sydney	Yes
5	St George Hospital	Sydney	Yes
6	Prince of Wales	Sydney	Yes
7	St Vincent's	Sydney	Yes
8	Sutherland	Sydney	Yes
9	Bankstown	Sydney	Yes
10	Blacktown	Sydney	Yes
11	Mt Druitt	Sydney	Yes
12	Liverpool	Sydney	No
13	Nepean	Sydney	Yes
14	John Hunter	Hunter / Mid Nth Coast	Yes
15	Illawarra Area	Illawarra / Sth Coast	Yes
16	Lismore Base	Nth Coast / Nthn Tablelands	Yes
17	Wagga Wagga Base	Sth Western NSW	Yes
18	Corrections Health	NSW prison population	Yes
19	Bega District	Sth Coast / Sthn Tablelands	Yes
20	Orange Base	Central / Far West	Yes

Interferon does have side effects. If you are thinking about Interferon, there is written information available. A good doctor who is up to date on hepatitis C will provide information also. Your Council has information available too (see page 16).

You should find out as much as you can about the treatment. If you are keen on Interferon, a consultation with a liver specialist will be part of the Section 100 evaluation process. Here, you should have your concerns and queries written down so you don't forget to ask about them. Make sure you find out as much as you can.

If you are eligible for Interferon treatment and you've decided you want to try it, you'll end up attending the treatment centre where you should be briefed on treatment and side effects. You will be supplied with take home supplies of the drug and will have to return for regular monitoring and further supplies. Your condition will be further monitored for 6 months following the treatment to determine how successful it was. Currently, around 25% of people who try Interferon achieve a long-term remission.

NB. If anyone who has been on Interferon wants to be taped in a short video program, please contact Paul. This video would be very useful for people who are deciding whether to try the treatment.

RURAL ISSUES - ON THE BORDER

(Continued from page 9)

- some group members had multiple serious ailments which had a distracting effect on group solidarity and identity;
- a matter of scale and geography;
- the combined population of Albury / Wodonga is approx. 80,000. By comparison, this hardly represents more than a small Sydney suburb;
- efforts to achieve autonomy were diffused by the cumulative effects of the above.

In Albury, we only have three 'major' shopping centres and in this concentration of interaction, personal or group autonomy and independence will be seriously challenged.

I certainly don't want to sound as though I'm generalising, but my experience of the myth of the 'supportive, welcoming and friendly country town' is that it can have a hostile and defensive underbelly when existing social structures and value systems are challenged by anything seen as 'different'.

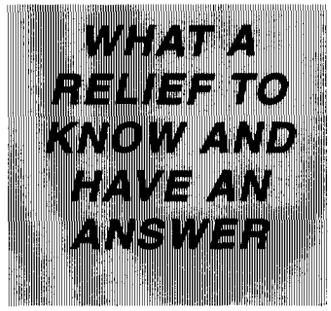
I suppose our situation could have been improved by a large scale public education programme. It also appears that mainstream research and medical data is progressing at a pedestrian pace and obviously this has a profound effect on various levels of government policy formulation.

In the meanwhile all I can say is thank god for the Hep C Council and alternative therapeutic practices, and I look forward to the time that it is acknowledged that we urgently need healthcare workers in this field to develop effective ongoing services.

TANYA'S STORY

I have finally found the reason for all my tiredness and sickness - yes, its hepatitis C.

My husband and I ran a business for five years where I literally ran everything (except classes). It was a Martial Arts centre and my husband was the teacher. My daily life involved 10-12 hours of work and over the five years, I had three wonderful children. It seemed I never had chance to stop. I was the typical 'super mum' - business, home and babies.



Towards the end of my third pregnancy, I said to my husband that I thought I needed a rest. I had about a week to go. My husband freaked - I had done it all and now wanted a rest.

Unfortunately he could not cope and left, yes left! After the birth and five days of rest in hospital, I went home to the reality of three children and a separation.

My baby is now nearly six months old and since his birth I have suffered terribly with tiredness and have been unable to fight off four bouts of flu.

I firstly said to my doctor that maybe there is something wrong with me. I had been told continually that my poor health was due to my recent pregnancy and separation. The strain of the previous five years was also mentioned as being a possible factor in my 'burnout'. Perhaps, it was suggested, I had one of these terrible flu viruses - it was winter after all.

(Continued on page 12)

I FEEL TIRED DOC, WHAT'S THE MATTER WITH ME?

We recently spoke to Dr Chris Liddle, a leading hepatitis C clinician working at Westmead Hospital NSW. Dr Liddle spoke of the confusion surrounding tiredness and lethargy - a classic hepatitis C symptom - and of what can be done about it.

People with hepatitis C who experience tiredness might easily assume that because their liver may be damaged, they are possibly not getting enough energy - the liver plays an important role in processing raw fats and sugars into a more usable form of energy. The suggestion that the liver is letting us down and not delivering the energy we need is mistaken.

Dr Liddle stressed that the tiredness and fatigue associated with hepatitis C infection is nearly always caused by the hormones, chemicals and other substances released into the blood as a result of illness. He said the liver itself, could function adequately even when seriously damaged. He added that liver function was only noticeably impaired if someone was experiencing end-stage liver disease, and that this will only ever affect a small number of HCV positive people - probably less than 10%, and even then after 20-30 years.

"People who are worried about tiredness and add high-energy diet suppliments to their diet are simply going to put on additional weight" Dr Liddle stated. "The recommended diet for people with hepatitis C involves a well-balanced diet that is low in animal fats".

[Cutting down on alcohol intake and eating a well-balanced diet are commonly recommended lifestyle changes for people with HCV]

WOMEN AND HEPATITIS C - WHAT ARE THE ISSUES?

A SHORT REPORT BY JENNIFER HOMES - DRUGS IN PREGNANCY UNIT, ROYAL PRINCE ALFRED HOSPITAL

A women's experience of hepatitis C infection is probably similar to that of a man's, but who is to say? Women, after all, are often under-represented in research studies.

We have a need for gender-specific, factual information about the progression of the infection, healthy lifestyles and avoiding transmission.

Specifically, we have need for hepatitis C information relating to treatments, pregnancy and breastfeeding, hormonal effects and the use of hormonal contraceptives. Also needed is information on transmission of the hepatitis C virus (HCV) to children, sexual partners and household members.

As avoiding harm to the liver is very important for people infected by HCV, we need to know about safe levels of alcohol use for women. Women need to understand that alcohol is dangerous to the liver and that it would be best not to drink at all. If we do, it is best to avoid binge drinking, drink infrequently and no more than the normally recommended range, ie. no more than 2 standard drinks in 24 hours.

Women need to understand what is involved in Interferon treatment. It is not uncommon to experience side effects to interferon that are distressing, especially if one has not been forewarned. Such symptoms include menstrual irregularities, hair loss and tiredness.

Tiredness, it should be pointed out, can affect people in differing ways. Not only can it make getting through the day seem a chore, it can also lead to changes in daily patterns of work and exercise. Some women invariably put on weight which can negatively affect their self image. It's important that women get good information on nutrition and diet.

Women may also experience menstrual irregularities as a consequence of hepatitis C infection itself, particularly at times of acute symptoms. Abnormal bleeding may occur at these times so it is important that a woman's general health be checked as well as her liver function, eg. part of a general health check-up should include the monitoring of pap smears to rule out cervical cancer.

In general, it may be better to use the oestrogen-containing pill but during times of significant exacerbation of hepatitis C infection, it might be best to use a progesterone containing pill.

How do you know if your infection warrants it? Talk to your doctor about this. Consider if you are experiencing a lot of symptoms, or if your liver function test results are significantly elevated or fluctuating.

"WE HAVE A NEED FOR GENDER-SPECIFIC, FACTUAL INFORMATION."

Progesterone-only contraceptives are thought to be less irritating to the liver but caution should be used if liver problems are present.

Those women considering hormone replacement therapy should have a thorough initial assessment of liver function before commencing therapy, and then be routinely monitored throughout therapy.

Sexual transmission of hepatitis C is thought to be very uncommon although all sexually active people

Tanya's Story *(continued from page 11)*

Then, one Saturday when I was feeling so exhausted, I walked across the road to my doctor, and thank the Lord, she suggested a blood test including a liver function test.

When test results came back, I found out I was hepatitis C positive as well as having irregular liver function test results. I remember how vivid the statement seemed - in big red letters - "HEPATITIS C ANTIBODIES POSITIVE".

What a relief to know and have an answer. I knew with all my support from Church and God that my separation and third child were not the sole reasons for how I had been feeling.

I am having a liver biopsy in a couple of weeks and I can only pray that I will be healthy and healed for my children's sake. I have been a Christian for eight years and thought I had escaped falling into any sickness.

However before my encounter with God, I used drugs and sharing needles was a normal occurrence. I find this a little difficult as it means I have had this hep C for around 8-12 years, just waiting to be discovered.

Since my discovery, I told a few friends at the Church. Praise the Lord, I now know I am not alone. There are at least three of us at the Church who are hepatitis C positive.

I am hoping that maybe we can have a support group started in our area as we have the facility and one of us is a trained social worker. Maybe the Hepatitis C Council will be able to help?

Thank you for your help so far.

need to consider safe sex because of the wide range of sexually transmitted conditions.

Safer sex that involves use of condoms is recommended during menstruation and if either partner has any genital lesions.

Traumatic sex, which has the effect of increasing the risk of viral transmission, can be avoided by ensuring adequate lubrication. If necessary, use one of the commercial water-based sexual lubricants available in supermarkets and chemists.

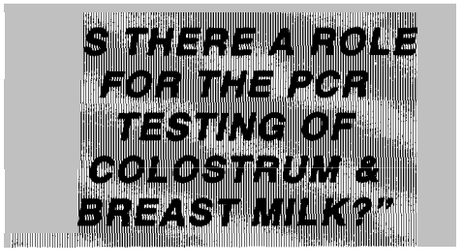
Vertical transmission (spread of the virus from mother to baby during pregnancy or at birth) is very low and thought to occur in less than 10% of pregnancies involving HCV+ mothers. Vertical transmission seems to depend on the mother's viral load at the time of pregnancy. Perhaps there is a role here for the particular PCR tests that can measure a person's viral load.

Women who are hepatitis C+ do not need to consider termination of pregnancy because of their HCV status as some misguided people suggest.

Breast feeding remains a controversial topic. If breast and bottle feeding provided the same benefits to an infant, then the choice would be easy - hepatitis C positive mothers would be safer to bottle feed. However, there are many advantages to breast feeding and the possibility of transmitting the virus through breastmilk is thought to be remote.

The decision to breastfeed or not needs to be made by parents, after a discussion of benefits over risk. Is there a role for the PCR testing of colostrum and breast milk before a decision is made by the parents?

Health authorities recommend that babies born to hepatitis C+ mothers should have a hepatitis C antibody test when they are around 18 months of age. During this time most babies will have lost the mother's hepatitis C antibodies that were passed across the placenta. They will therefore show correctly as hepatitis C negative.



Babies that test hepatitis C positive at eighteen months should be repeat tested as they may simply be slower to clear the mother's antibodies. Repeat testing can be undertaken when they are older or other blood tests such as PCR may need to be performed.

The testing of older children is a difficult dilemma for parents for a number of reasons. The transmission rate is low during pregnancy and delivery, and even less likely through casual contact at home. If the result is likely to be negative, why expose the children to blood tests?

There is currently no vaccine although free treatment is available for adults and children via the Section 100 Interferon treatment scheme.

The most important messages for women who are hepatitis C positive are:

- **hepatitis C is a chronic,** slowly progressing illness that few people die from, however significant lifestyle changes should be made to maintain quality of life and prevent transmitting the virus to others;
- women need to be aware of the recommended safe level of alcohol consumption. This is 1-2 standard drinks in 24 hours, and limit drinking to 3-4 days a week;
- women should consider giving up alcohol altogether if their liver is damaged;
- the hepatitis C virus is spread through blood-to- blood contact. Casual or household contact will not spread HCV;
- people should not share razors, toothbrushes, nail files etc. or expose themselves to practices which involve the transfer of blood.

BREASTFEEDING GETS THE THUMBS UP

Hepatitis C-positive mothers can breastfeed their babies, Melbourne researchers say.

Breastfeeding is not a major risk factor for maternal-infant hepatitis C transmission, even in mothers with detectable [virus in their blood] according to a study reported in a letter to the *Medical Journal of Australia* (17 July 1995).

"We would no longer recommend against breastfeeding in hepatitis C-positive mothers, except perhaps in those cases where there is a high level of exposure to blood from nipple trauma," said Dr Scott Bowden, senior research scientist from the Victorian Infectious Diseases Reference Laboratory.

"In our study, 16 of the children had been breastfed and none had any signs of hepatitis C. Nor did the 11 children who had potential exposure to blood through either cracked or bleeding nipples or needlestick injury."

Abridged from Jo Stratmoen's article taken from *Australian Doctor* (4 August 1995)

(Continued from page 2)

a significant number of clients experience a normalising of LFTs in 6 months. Hepatitis-related symptoms seem to decrease at the same time.

Prof Chen also noted that herbal treatments had varying levels of success depending on the individual patient's virus genome subtype.

"The Australian government is keen to see the development of any cost effective treatments that really work for people with hepatitis", added Prof Batey.

He went on to say that phase two of the trial running at John Hunter Hospital will involve the patients receiving tailored treatments according to their individual cases. Combination therapies would possibly also be used.

Prof Chen is here in Australia leading a teaching clinic at the Sydney College of TCM, Leichhardt NSW. Patients attending the teaching clinic receive treatment similar to that used in China.

"Demand for this TCM treatment has been great. We do not need to advertise for the low-cost weekly treatment as all places are full," said college principal Mr Garry Seifert.

Local TCM practitioners also use herbs and acupuncture for treating hepatitis. Christine Berle, a director of the Australian Chinese Medicine Education and Research Council, said "the Australian Health Ministers Advisory Council is reviewing the need for registration of acupuncture, Chinese medicine and naturopathy."

"Until then, people need to ensure they see a practitioner who is a member of an established professional body and experienced at working with people with hepatitis."

(see editorial - *Hep C Review* No 10, Mar 1995)

ST VINCENTS PCR TEST RESULTS

Abridged from Phil Kearney's report - Haematology Dept, St Vincents Hospital.

Hepatitis C detection methods at St Vincents Hospital have been expanded to include the use of PCR viral testing.

This technique is thought to better represent detection of true infection since the viral RNA (a basic part of the HCV virus) is the basis of detection rather than the human antibody (which is manufactured in response to presence of the virus).

Antibodies may still be in present in the blood even though the virus is no longer undergoing replication.

Within the last 11 months, St Vincents Pathology has received 294 samples for Hepatitis C PCR analysis and the results are tabled below.

The antibody status is given as positive (+), negative (-) or uncertain. The last category may have arisen where the antibody test result was indeterminate or where two types of tests showed differing results. St Vincents uses both Abbott and Murex tests to determine HCV antibody status because they detect different components of the antibody.

The PCR method is most useful in determining which HCV antibody+ patients have detectable virus present.

antibody status	PCR result	No. of cases
positive	positive	102
positive	negative	64
negative	positive	6
negative or unknown	negative	68
unknown	positive	46
uncertain	positive	1
uncertain	negative	7

Around 22% of antibody(+) patients were found to to be PCR negative, a finding which is in accord with other research.

PCR has also been useful in resolving the 3% of antibody tests that have given uncertain results.

The test also shows that 2% of antibody(-) results were PCR positive, which demonstrates the different sensitivity of various hepatitis C tests.

While the value of knowing a blood sample is PCR negative remains relatively controversial, these results generally confirm the importance of PCR in fully evaluating patients with chronic hepatitis C infections.

INTERFERON RETREATMENT TRIALS

A SHORT REPORT FROM PROF GEOFF FARRELL, WESTMEAD HOSPITAL

People who have relapsed after Section 100 Interferon treatment, may be able to try it again through a trial currently running at Westmead Hospital.

The trial is a fairly demanding one, including an initial course of retreatment and then the possibility of either on-again off-again treatment, or continuous interferon for up to four years. The trial will require 2 or 3 further biopsies.

Patients who tolerated Interferon well and are concerned about the possible progression of their disease should speak to their doctor who can contact Sue Treloar for a synopsis of the trial (ph. 214 8922, fax. 635 7582).

This trial is being carried out in conjunction with a second similar trial at St Vincents Hospital, Melbourne.

NEWS 'FROM THE HUNTER BRANCH

A REPORT FROM LEONE ROBERTSHAW

The signing of the lease to our office and receiving the keys was simply a wonderful experience. I remember when I first found out we had got the office, I phoned Lee-Ann and wanted to 'jump down the line and give her a hug'. All of us at the local group were just so ecstatic.

Following the lease signing (and photos etc.) we got down to the practicalities.

We definitely needed to paint the office. The previous tenant had left it ala aqua-green and lime-yellow, so we all got in together and freshened it up a bit with a bit of paint. Big thanks go to Don Watts, Helen and Alan Potts, Melinda Ferguson-Finn and Jessie; my husband John and Ami-Lee and Dean.

There were nine very sore bodies in Newcastle that night - a tired but happy team.

The next job was furniture. We were very fortunate that the Newcastle City Council kindly agreed to donate some furniture, along with the Newcastle Hospital and Hunter Public Health Unit. We owe a great deal of thanks to Bob, Lee-Ann and Alan from the Council; and to Lyn and Dr John Stephenson from the hospital and Public Health Unit.

We still had to arrange the phone and fax, the blinds and all the stationery needed to get the office running (as opposed to just existing).

We now have a good office and a sound team behind it. The Hepatitis C Council - Hunter Branch is staffed by committed volunteers and overseen by a local advisory committee.

This service is dedicated to assisting local people who have been adversely affected by hepatitis C. Within all the hard work getting to this point, I would like to add thanks to some people not mentioned above. These include Professor Bob Batey from the John Hunter Hospital, Tony Butler from NSW health and Dr John Stephenson's staff - Betty, Anne, Lynette and Lyn. Thanks girls, it's great to have been made to feel so welcome.

We owe thanks to Dr Malcome Roe as well. He has assisted greatly in spreading the news of our group amongst healthcare workers in the Hunter region.

Lee-Ann Birjuk from Newcastle City Council hands the new keys to Leone Robertshaw, convener of the local group.

THE NEWCASTLE UNI HEP C STAND

A special report by Melinda Ferguson-Finn.

From 24-28 July, there was an information stand at Newcastle University, set up to raise awareness of hepatitis C.

It was an excellent start towards raising awareness in our community. We distributed over 200 brochures and answered various questions that people had.

It was obvious from our contact

(Continued on page 16)

INTERNATIONAL TREATMENT PLAN REFLECTS LOCAL FINDINGS

Australian research has been central in the development of an international consensus policy on hepatitis C management which calls for Interferon to be given for at least 1 year.

Professor Geoff Farrell said a recent international conference acknowledged that extended treatment halved the relapse rates seen after 6 months therapy.

Prof Farrell said the PBS allowed only 6 months' interferon therapy, but he understood the Pharmaceutical Benefits Advisory Committee was considering changing the listing in the next few months to allow longer treatment.

Geoff said the consensus conference held in Los Angeles in May this year based its recommendation largely on an Australia-wide trial of interferon involving 230 patients.

He added that the relapse rate fell from 65% to 30% in those patients who took interferon for 1-2 years.

"Another positive finding is that those people who take the treatment longer and don't relapse after stopping tend to stay cured."

Medical and scientific editorials have welcomed the findings while at the same time, sounding a note of caution by highlighting the considerable costs involved with longer treatment strategies (see our editorial).

They say that treatment with interferon should be considered both for patients with a high likelihood of progressive disease and those most likely to respond well to the treatment.

Abridged from Jo Stratmoen's article in the *Australian Doctor*, August 1995.

Information available to all Council members.

These resources are available free of charge, or for a low cost that covers postage.
(Videos are borrowed for two weeks at a time. You will need to pay the return postage of $3.00)
The Council's postal address is PO Box 432, Darlinghurst, NSW 2010.
Our phone number is (02) 332 1599 and our fax number is (02) 332 1730.

Item	Description	Cost?
Hep C Information Booklet	An overview of hepatitis C, including testing, treatment, biopsies, haemophilia, lifestyle changes, prevention, drug use, women & hep C, prognosis and a hep C glossary.	none - it is sent to all new members.
Newsletter back issue pack	Topics include Social Security, Disability Support Pension, Interferon treatment, natural therapies.	none
Video No.1	Prof Geoff Farrell discussing Interferon treatment, plus Jennifer Holmes discussing women & hep C.	$3.00 return postage
Video No.2	Ken D'Aran discussing homeopathy, plus Raymond Khoury discussing herbalism.	$3.00 return postage
Video No.3	Women and Hepatitis C Forum - featuring Dr Ingrid van Beek, Ses Salmond and Cheryl Burman.	$3.00 return postage
Video No.4	Quantum episode - dealing with the Liver	$3.00 return postage
Video No.5	Interferon video (from Schering-Plough & Roche)	$3.00 return postage
Detailed Info Pack No 1	includes recent research papers on overview, prevention, diagnosis, serology, epidemiology.	none
Detailed Info Pack No 2	includes the AGI and Fairfield Hospital healthcare provider booklets and the National Hepatitis C Action Plan.	none
Detailed Info Pack No 3	includes the NHMRC Hepatitis C Report (1994) and the WA Health healthcare provider booklet.	none

(Continued from page 15)

with the general public, that much misinformation about hepatitis C exists.

People asked about where to get the hep C vaccine, and if their hep B vaccine would protect them. Some wondered just how long hep C disease lasts. Others approached gingerly, eventually admitting they thought it was like AIDS.

I would like to thank the following people who were involved in the planning and staffing of the stand - Steve, Alan & Helen, Wendy, Glyn, Robyn and Robyn, Rita, Rose and her father, and Leone.

The event impressed on us all the need for further information and education in our community.

- **Melinda Ferguson-Finn**

HEP C AND STH SYDNEY COUNCILS MEET

Cr. Vic Smith, Mayor of South Sydney Council, will meet with the Hepatitis C Council of NSW to discuss present hepatitis C related problems for the South Sydney area, and the future health and social implications of the epidemic.

The South Sydney local government area takes in a population that experiences some of the highest prevalence and incidence rates of hepatitis C infection across the state. The Hepatitis C Council of NSW welcomes any interest from local government areas as local government is responsible for many community support services appropriate for people with chronic disabilities.

At the forthcoming meeting, parties will discuss the direct resourcing of community-based support groups, as well as the Hepatitis C Council's current need for long-term office accommodation. Discussion will also focus on health promotion campaigns that would hopefully lead to better quality of life for those already affected, and reduce further transmission of the virus.

South Sydney Council representatives attended the Hepatitis C Council sponsored parliamentary briefing held late last year. We welcome South Sydney Council's ongoing interest in hepatitis C developments.

SOUTH COAST NEWS

A short report by Bev, from the South Coast Hepatitis C Support Group.

On 11 July we had a public information night at the Nowra Community Library. About 25 people attended. We felt that because Nowra is a small community, many people were unwilling to be identified as being affected by hepatitis C.

Bulli MP Ian McManus spoke of the close personal contact he had with people with HCV.

"The amount of ignorance about hepatitis C really does disturb me" he said.

He called for much greater Commonwealth Government resourcing, more education of health professionals and in the community, and emphasised his support for local people affected.

"More people need to stand up and be identified," Ian said. "It's much easier to do it as a group. The effect won't be as bad as you think." Ian McManus is a strong supporter of the Hepatitis C Council of NSW, and works tirelessly to raise the profile of hepatitis C within Parliament.

Dr Jenny McDonald of Illawarra Public Hospital and Desolie Lovegrove spoke on the clinical and statistical aspects of hepatitis C. Bev spoke about her personal experiences and Stuart Loveday talked about how the community sector, with organisation and support for one another, could harness great power to bring about change.

Our thanks to David Read, Drug and Alcohol Counsellor with the Dept of Health in Nowra for his great organisational and moral support.

More recently we've had links with a Health Dept worker from Goulburn, keen to draw on our experience in setting up a local support group there.

We're encouraged by this: anything we can do is really necessary for those of us living in the country.

It shouldn't just be up to us however. Government workers don't seem to get much backup from the Health Dept. It should be organising information and education seminars for health and welfare workers all over NSW.

There should also be public awareness campaigns that will address the discrimination most of us live with day in, day out.

TEENS GET CUT-PRICE INTERFERON

Patients aged under 18 will now be able to access free interferon treatment following changes to the Pharmaceutical Benefits Scheme (PBS).

Previously, a marketing approval and subsequent PBS listing of the drug for use only by people over 18, meant that young people with chronic hepatitis C had to pay for their own treatment. The cost of a 6 month course costs between $2-3,000.

A spokesperson for the federal Department of Human Services and Health said the PBS change followed complaints that the system disadvantaged children with haemophilia who contracted hepatitis C through blood transfusions.

Abridged from Charlotte Wood's article in the *Medical Observer* 4 Aug 1995.

VICTORIAN CAMPAIGN PROVIDES MORE HCV INFO

A desire by Australian health ministers to shift the management of hepatitis C from specialist gastroenterologists to GPs underpins a campaign to educate family doctors about the disease, according to Justine Rowe.

Mr Rowe, the Victorian Health Department's hepatitis C educator and counsellor, helped organise the campaign which was launched this week.

The major campaign components include:

- a program of treatment and counselling seminars for GPs and other healthcare workers, to be held in metropolitan and regional centres
- a hepatitis C inquiries line for healthcare providers
- a clinic specifically for individuals and couples affected by hepatitis C

Mr Rowe said the GP seminars would be provided through divisions of general practice. They would attract CME points and would be free or have a nominal fee.

He is establishing contact with agencies working with people who inject drugs and other people at high risk of contracting hepatitis C.

"The long-term aim is to develop and maintain a hepatitis C network that ensures healthcare workers and counsellors have access to accurate and up-to-date information," he said.

Further information about the courses can be obtained from Mr Rowe on (03) 9288 4127.

Abridged from Ann Westmore's article in the Australian Doctor 4 August 1995.

THE NEXT ISSUE - THE HEP C REVIEW

Although there will always be a range of articles, in each newsletter we attempt to target particular topics.

For example, No 9 focused on interferon treatment. No 10 dealt with natural therapies. This edition carries articles dealing with rural living, and women and HCV.

What you want to read in future editions can be determined by you. Simply phone the Council and let us know. Or when you write to the editor, state what you want to see.

The next issue is going to focus on the prison system. The prison environment involves major gaps in prevention strategies. Gaps also exist in regard to treatment.

If you have experience of prison, either as inmate or worker, write in to the office with a letter or article.

Deadline for the next edition is 17 November.

MEMBERSHIP NEWS

Each time a newsletter mailout goes out some are returned marked 'return to sender'.

To lessen our paperwork, please phone or write to the Council if you are changing address.

Our Council greatly appreciates the work done by our many volunteers. We have recently fine-tuned a volunteer database and this will make it much easier to keep in touch with those people interested in getting and remaining involved.

If you want to help in any way, give me a call. I will enter your name on the computer. This will enable us to contact specific people when a specific project comes up.

Paul Harvey

Tel (02) 332 1853

WOMEN AND HEPATITIS C INFO NIGHTS

at Leichhardt Women's Community Health Centre

LIVING WITH HEPATITIS C

A workshop to explore issues faced by women living with hepatitis C - disclosure, relationships, sexual health, long-term health plans, pregnancy and parenting, legal and medical issues. Come along and take part in an informal discussion led by a panel of experienced health workers.

Tuesday 14th November 7pm

For more details and to enrol ring 560-3011

Leichhardt Women's Community Health Centre is funded by the NSW Health Department

55 THORNLEY STREET, LEICHHARDT

HEPATITIS C STUDIES SEEK YOUR VIEWS

We have been approached by a post-graduate student from the Bond University, QLD, seeking assistance with his thesis project. This project investigates the psychological effects of having contracted HCV.

This coincides with a separate research project also featured in this edition of The Hep C Review (see lift-out section). It's good to see there are people wanting to research the day-to-day situation of those of us who have HCV. We would like to highlight how important such work is. Without such formally acknowledged research, it is difficult to persuade bureaucrats and other decision-makers of the need for positive action.

If you are interested in attending a meeting (30 min) with the researcher please contact the Council and we will provide details. Our phone number is 02 332 1599 / 1853.

Interviews can be held at the Council office, Surry Hills. Please consider this important, worthwhile and confidential request.

COUNCIL TO ADOPT NEW CONSTITUTION

Changes to our existing constitution have been sought for some time and an ongoing process of review has culminated with a present proposal.

The basic changes provided for in the new constitution, include

- the method of electing the management committee
- the size and make-up of the management committee

The process of review has been carried out by John MacKenzie, Stuart Loveday and Paul Harvey. Throughout the process, legal advice was sought from Graham Wheeler, a lawyer well known for his work with community-based goups such as ours.

Overall, the new constitution builds on basic legal requirements and has been modeled on a draft provided by the AIDS Council of NSW. This has helped us greatly and we appreciate ACON's ongoing assistance with such matters.

Specifically, the new constitution provides a say for all people across NSW in the **election of the management committee** at the annual general meetings. A postal system of voting will be used if there are more candidates than positions vacant. This process will make the organisation more democratic and accountable to you, the members.

New rules for the **make-up of the committee** will enable more people to get involved in this important role. We shall be able co-opt people with specific skills and at the same time, we will guarrantee representation for rural people affected by HCV, and people who inject drugs.

The proposed changes will lead the organisation onwards and upwards. They co-incide with a natural need for the Council to grow and develop.

I urge all members to consider and support the proposed constitution.

Paul Harvey - Senior Project Officer

HOME & COMMUNITY CARE

The Hep C Council has begun an outreach drive aimed at contacting the hundreds of Home and Community Care (HACC) organisations across the state.

Home and Community Care is a cost-shared program between the Commonwealth government and the State/Territory governments. The program assists many older people and people with disabilities to live independently in their own homes. It aims to enable these people to continue to participate in their local communities.

The HACC program provides services such as home help and maintenance, personal care, community nursing, meals on wheels, respite care and transport.

HACC also helps the carers of these people through assisting with caring tasks or by giving them a break. It also helps carers by providing information, training and education.

To date, the Council has contacted over 500 HACC agencies in the NSW coastal region. Our next contact campaign involves the Central / Far Western NSW region.

Such work will lead to better access of existing local support services for people affected by HCV.

(Continued from page 5)

EDUCATION (FOR) PREVENTION

injecting drugs share their equipment. Therefore it was felt that if those current experienced users who initiate new users were properly educated about the risk of sharing **any** equipment, and could pass that safer use information on, then that work should be the first priority to be funded.

Other priorities for transmission reduction were:

- expand harm reduction
- education and promotion through existing injecting drug use (IDU) agencies
- bringing about change in prison environment to ensure safe drug use; this would involve expanding existing harm reduction strategies, especially the prison methadone programs and needle and syringe exchange programs (NSEP)
- targeting family members for IDU prevention messages, not just for care and support of their relatives and friends with hepatitis C
- existing health information services would need to be strengthened and better defined
- targeting unregistered skin penetration practitioners
- expanding life education programs in schools
- providing better, more up to date information and education for GPs and other health care professionals
- distributing more information through chemists, community health centres, welfare agencies etc.

The education/prevention strategy is just one part of the National Action Plan. A small working party has been drawn from different sectors within different states. This working party will advise on strategies on how best to involve the targeted groups in transmission reduction.

This advice would be given to AHMAC. As community groups, we need to ensure that this action is followed up to ensure the most appropriate work is done to lessen the impact of hepatitis C. **If you have suggestions, contact Stuart on (02) 332 1853.**

MEMBERSHIP FORM - please photocopy & return this page

Please complete as much of this form as possible. Our policy is to respect your privacy. All details on this from are treated in the strictest confidence and all communication is carried out discreetly. Please photocopy, complete and **return this form with cheque, money order or credit card details to**

PO Box 432
Darlinghurst NSW 2010

Cheques should be made out to Hepatitis C Council of NSW

1. Please complete one of the following sections.

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

Name			
Street address			
Suburb / Town			
State		Postcode	
Hm phone		Wk phone	

b) For individual healthcare or welfare professionals.

Name			
Position			
Postal address			
Wk phone		Wk fax	
Mobile phone		Email	

c) For agencies, companies and corporations.

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

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

Admin and office work?	
Helping with large mailouts?	
Writing newsletter articles?	
Video production?	
Phone support work?	
Local branch work?	
Public speaking?	
Facilitating support group meetings?	
Management Committee work?	
Other?	

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

Renewal		New member	

4. Listed below are our membership fees. Please circle one fee box.

Membership fees are due annually on 1 March. We would welcome a full year's payment, however we would not want financial hardship to prevent you from becoming a Council member and receiving *The Hep C Review*. If this is the case, please phone the office.

INDIVIDUALS		ORGANISATIONS	
Concession	$10	Community-based	$50
Waged	$25	Public sector	$70
Professional	$40	Commercial sector	$70

5. Separate donations are gratefully accepted by the Council.

These are tax deductible. If you make a separate donation, please record the amount and whether you want your support mentioned in our newsletter.

$ for publication? yes / no

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

Full name _____

Card number | | | | | | | | | | | | | | | | |

Card type (please circle) Mastercard Visa Bankcard

Expiry date month _____ year 19

Cardholder's signature _____

7. Declaration.

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

Signed _____ Dated _____

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

In regard to page 11's article *"I feel tired Doc, what's the matter with me?"* please note the following comments.

Fatigue is common within the general community. Clearly, hepatitis C is not the only cause of fatigue and indeed, only about 50% of patients with hepatitis C complain of fatigue. Having said that, there is a small group of people with hepatitis C with severe fatigue and it seems that it is the hepatitis C that is causing the fatigue (Interferon can lessen the tiredness and fatigue in some of these patients).

Doctors and specialists do not yet fully understand the cause of fatigue associated with hepatitis C, but one possibility is that liver inflammation associated with HCV infection may release chemicals into the blood. These chemicals are called cytokines and may induce the feeling of fatigue. It must be noted though, that this belief is yet to be proven.

A diet lower in animal fats is not necessarily essential but in general, people with hepatitis C should adhere to a normal healthy diet. One of the best lifestyle changes one can make is to control or give up drinking alcohol. There are some studies that suggest that the combination of alcohol and hepatitis C act together to cause liver damage. This is not surprising, given that alcohol on its own is a risk factor for liver disease.

If you drink alcohol, try to limit yourself to 7 standard drinks (or less) over a week. Consider drinking low alcohol drinks and alternate these with non-alcoholic drinks (eg. have one lemon squash for every beer). Try avoiding situations where there is pressure to drink heavily and **avoid binge-drinking**.