The Hep C Review

Summer Edition, January 1996 Issue 13

NATIONAL epidemic- NATIONAL response

People who are affected by hepatitis C could soon be represented on a national level by a national peak body for hepatitis C community organisations.

In November, the first meeting of seven state and territory hepatitis C groups was held. The meeting was hosted by the Hepatitis C Foundation of Victoria and took place in Melbourne, coinciding with the 3rd Australian Symposium in late November 1995.

Representatives of people who contracted hepatitis C through blood products and transfusions attended the meeting, and people who

(Continued on page 17)

Pictured at a recent meeting, the NSW Minister for Health, Dr Andrew Refshauge with representatives from our Council. Full story on page 2.

PRISONS - what do they mean to you?

As tax-payers, we all pay for our prison system in exactly the same way we fund our hospitals and schools. We therefore have a direct stake in the way prisons are run.

The fundamental aims of the NSW prison system have changed over the years, with the current focus being rehabilitation.

Although people have different views on how prisons should be run, it must be acknowledged that prisoners (sentenced or on remand) retain basic human rights.

prisoners should be able to access the same medical services .. that many of us .. take for granted.

We feel that prisoners should be able to access the same medical services and disease prevention measures that many of us in the general community take for granted.

This edition of the Review focuses on our prison system. We hope this will encourage useful public debate.

EDITORIAL

Prisons are part of the community, and prisoners are members of the general population. Health services and prevention measures in prisons should be the same as those available to the rest of the community.

Hepatitis C has emerged as the most significant public health issue for the prison system. Around 40% of prisoners are hepatitis C antibody positive. Such a disturbing high prevalence of the hepatitis C virus (HCV) is a dire warning against complacency regarding the management of other blood borne communicable diseases, such as HIV, within the prison system.

In prisons, as in the general community, promotion of safer behaviour is far more likely to be effective than attempted suppression of risky behaviour if we are to contain the spread of blood borne communicable diseases, such as hepatitis C, hepatitis B and HIV.

A major part of Australia's early response to HIV/AIDS was the introduction of an effective range of harm reduction measures. Experience has shown that pragmatic and effective measures, such as needle and syringe programs, can receive acceptance within the wider community, once their impact as a prevention strategy is understood.

It is now vitally important that we do not undermine these initiatives through negligence in areas such as prisons. Our community cannot afford out-of-sight, out-of-mind attitudes.

Prisons will have either a valuable or ultimately destructive roll to play in managing the spread of all blood borne communicable diseases. They provide an opportunity to deliver prevention programs to some individuals who practise high risk activities, but who may not otherwise be exposed to such programs while in the general community. This opportunity must be acknowledged and accepted by the Departments of Health and Corrective Services.

The Hepatitis C Council of NSW acknowledges the important and progressive steps already undertaken in prisons. In particular we welcome the expansion of the HIV/AIDS Peer Education Project to include all forms of hepatitis, the establishment of the prison methadone program, the establishment of a tattoo project for prisoners and the envisaged trial of condom distribution. However, the real work remains to be done. Existing high prevalence of HCV infection, combined with high levels of risk behaviour and limited access to safe injecting and safe sex equipment means that the potential for transmission of hepatitis C and other blood borne communicable diseases between large numbers of prisoners still exists. The practice of sharing injecting drug injecting equipment, known to be the major means of transmission of hepatitis C, must be addressed.

The proper implementation of a wider range of harm reduction measures in prisons is urgently required. The Australian Medical Association's vice-president, Dr Keith Woollard, released a statement in support of this, calling for the introduction of needle exchange programs in prisons to combat the spread of hepatitis and HIV.

The Hepatitis C Council of NSW was part of a project where community organisations jointly developed and published a policy that endorses the introduction of a needle exchange program in prisons as part of a comprehensive strategy to reduce the transmission of all blood borne communicable diseases. The policy also defines the appropriate care and treatment of positive prisoners and calls for the repeal of minor drug offences such as possession and self administration (see page 10).

People who inject drugs, Aboriginal and Torres Strait Islander people and people with an intellectual disability are groups of people who are significantly over-represented in the prison population (see page 17).

It is deplorable that serious health risks are imposed on these and other prisoners. How can our country be proud when basic human rights end inside our prison walls?

Minister for Health reaffirms commitment

Council members Stuart Loveday, Jennifer Holmes and Margaret Gearin, and Council Patron, Professor Geoff Farrell, recently met with Dr Andrew Refshauge, the NSW Deputy Premier and Minister for Health and Aboriginal Affairs.

Dr Refshauge announced a significant increase in funding for our Council leading to a doubling of our 1994-95 grant.

The Minister showed a keen interest in our Council, praising its high level of effectiveness, professionalism and its cooperation with the medical profession.

Dr Refshauge informed us that minimum service levels would soon be developed and built into public sector health delivery services across NSW.

"Because NSW has the largest proportion of HCV positive people in Australia, the Commonwealth has a particular role to play in resourcing HCV need," he said.

Dr Refshauge welcomed the proposed establishment of a national body for hepatitis C Councils and said it could only lead to greater benefit for people affected by hepatitis C.

We extended warm appreciation to the Minister for our increase in NSW Health funding, but acknowledged that we will continue to lobby both the NSW and the Commonwealth governments for greater resourcing for hepatitis C.

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

Since 1994, Margaret Gearin has spearheaded regional development in the New England area and is working towards coordinated local services for people with hepatitis C.

'FROM THE WIRE'
- NEWS FROM OVERSEAS

PARIS, Oct 25 Reuter - France unveiled today a national battle plan against hepatitis C, a disease that can go undetected for long periods in infected individuals only to emerge and cause fatal liver damage or cancer.
The health ministry said it would urge doctors to do more widespread testing for the disease, designate certain hospitals as centres specialising in hepatitis C care, and make the drug Interferon more readily available to patients.
The ministry announced the plan after receiving a report from it's National Public Health Network estimating that 500,000 to 650,000 people were infected with the hepatitis C virus in France though most were without symptoms.

CONTAMINATED RAZOR BLADES - A POSSIBLE SOURCE OF HEPATITIS C VIRUS INFECTION

Adapted from a letter by Andrew R Davis - Medical Officer, NSW Red Cross Blood Transfusion Service, published in the MJA 1995 : 163 : 275.

While it is accepted that hepatitis C virus (HCV) is transmitted primarily by blood, in some cases the source of infection cannot be determined. On reviewing the records of 39 Sydney blood donors identified as having HCV infection (by PCR) between 1 January 1994 and 30 April 1995 it was found that 10 (26%) had no recognised risk factor for HCV infection.

The possible role of contaminated razor blades in the spread of HCV has received little attention. A recent survey of 37 Sicilian barbers who shaved themselves with the same blades as those used for their clients revealed that 11 (30%) had HCV antibodies. This was compared to an absence of HCV antibodies in a control group of new blood donors from the same area of Sicily, and a prevalence of HCV antibodies in the general population of Italy of around 1.3%. None of the barbers or control group had any particular risk factors for HCV infection.

Razor blades (disposable and non-disposable) are used by barbers and hairdressers in New South Wales. It is currently recommended that non-disposable blades should be disinfected for 20 minutes in 2% gluteraldehyde if they are contaminated with blood. A potential for customer-to-customer transfer of HCV may exist if the contamination of the blade is microscopic and therefore unrecognised. Directly implicating a visit to a barber would be difficult, as barbers and hairdressers are not required to maintain detailed records of customers and HCV infection is usually unnoticeable.

Ideally, a fresh disposable razor blade should be used for each customer and promptly discarded after use. However, if blades are reused they should be sterilised, irrespective of whether blood contamination is noticeable or not.

LETTERS

To the Editor,

My husband 'Richard' was on the liver transplant list but he died on the 8th of August 1995. I am writing this to you to try and get my point across.

The day my Richard passed away, it was 1.57am and I rang our doctor at 2am, but he didn't come until 9.20am to sign the death certificate.

The workers from the funeral place did not come until 10am, so we had to sit with Richard for 7 hours and my children and I had to wipe up the blood that came out of his mouth and nose.

After they had taken Richard away, things seemed okay but at 12midday, I rang the funeral service to find out when we could have the viewing and I was told that this wasn't possible because Richard had died of hepatitis C. They said that hepatitis C was highly contagious and that people could catch it.

But what could we catch, I asked them. Richard had hepatitis C for 10 years and the last 6 weeks of his life, he had cancer. We had looked after Richard for over 10 years and hadn't caught the virus so what were we going to catch now all of a sudden? Maybe they were trying to safeguard their own men.

It was so hard for me to cope with what they said. It was as if someone had taken my whole life from me, or part of it anyway. I really think something should be done about it, if not for me, then for others like us.

Thank you, DA

The Editor,

I would like to thank you for sending me the video. At this stage anything is helpful as I only found out I have HCV 3 months ago.

My doctor gave me a blood test and then sent me to a liver specialist at Concord Repatriation Hospital and I've had another three blood tests. The specialist said I have a mild inflammation and I should think about a biopsy and Interferon treatment but I am very scared of having a biopsy because my Grandmother died of liver cancer. At first I thought the Interferon injections sounded alright but I don't know how long its been around for and I wouldn't want to be a guinea pig.

I believe the earlier you treat a sickness the more chance you have of cure but I don't know where to go from here. I am 34yrs of age and have a beautiful 17 year old daughter.

I used drugs for a while just after I lost my father. This was a month after my daughter was born and she is clear of having hepatitis C, thank God.

It looks as if I've had hepatitis C for many years so I don't know what stage it is at. I am very worried and confused and I don't know where to go from here.

If you can help me with more information it would be very much appreciated. It is very hard to speak with anyone as they don't understand.

Yours sincerely, GB

GB, a brief explanation of biopsies can be found on page 16. Interferon has been around for a while, certainly long enough for scientific trials. It has also been around long enough for stringent evaluation by the Commonwealth government.

If you want to talk to someone about hepatitis C related matters, phone our Information and Support Line on 1800 803 990.

To the Editor,

Thanks for your help and telling me about Welfare Rights Centre. I went to Social Security a week ago because I was appealing against their decision which meant I couldn't have the Disability Support Pension.

I had to go before a Tribunal called the Social Security Appeals Tribunal and they said things like I wasn't really sick and I couldn't have the pension. I am really angry though because they didn't look at my doctor's notes or recommendations. They just decided for themselves I wasn't sick.

Right now I am so depressed because of the way I was treated and because I had an argument on the weekend with my husband. Maybe he doesn't know how I feel or how disappointed I am. Its really hard to explain these symptoms and if I go on about them all the time, I feel like he thinks I am whinging. Luckily for me though, he is probably more understanding than lots of men.

I want to appeal against Social Security's decision because I think it was insulting the way they treated me. I am going to contact Welfare Rights Centre again and see what they say.

Thanks again, LB

We had a lot of problems with Social Security and the way they determined eligibility for Disability Support Pension. Welfare Rights Centre was instrumental in a campaign to have the eligibility guidelines clarified.

A final level of appeal is the Administrative Appeals Tribunal. I'm sure Welfare Rights can assist you again. They employ community solicitor who can advise or represent you. A future newsletter will focus on the Department of Social Security.

Letters to the Editor

(From Sydney Morning Herald 15/11/95)

Almost 500 young Australians die each year from drug overdoses. Shooting galleries in Kings Cross have for some years sold sterile needles and syringes to injecting drug users, collected and disposed of used equipment and provided as-

TO THE EDITOR

sistance to drug users who had taken an overdose.

They helped, together with officially sanctioned needle and syringe exchange programs, to control important infections including HIV, hepatitis C and hepatitis B.

Drug users who took an overdose in these premises had a far greater chance of surviving than if the overdose occurred in a dark lane or toilet. Littering of public places with discarded, used injection equipment was also reduced.

Given the current interests of the royal commission into corruption, the Police commissioner and the Premier are said to be considering alternatives. Several galleries have now been closed for fear that they could be used as evidence of police "corruption". The fragile control of major public health problems, such as infections associated with IV drug use, owes much to the far-sighted flexibility of many senior members of the police force throughout Australia, including tolerance towards shooting galleries despite them being illegal.

In regard to illicit drug use, a clear set of arrangements which safeguards the interest of the public health, the police and the community, are urgently required. The arrangements which developed informally and outside the law over several years in Kings Cross should be brought into the open and evaluated.

It is clear that these informal and pragmatic arrangements are now insufficient. A new "least worst" option needs to be formed, and formed quickly, to prevent deaths among IV drug users in the centre of our city. Special areas such as Kings Cross could benefit from changes in the law so that law enforcement does not lead to an increase in the damage associated with individuals' IV drug use.

Professor Stephen Leeder

National President -
Public Health Association of Australia

To the Editor,

In the *Hep C Review* No 12, I noticed a complaint about the phone service. To make things a bit easier, although not cheaper, the numbers, names and times could be stated in every *Review* and updated if necessary.

Thank you for doing such a good job for us all. My husband and I read the *Review* with interest.

Yours faithfully, Margaret.

We are in the process of bringing the phone service in-house and eventually, all volunteers will work from the Surry Hills office.

This will lead to a better service for people affected by HCV (and our wonderful volunteers won't have to answer calls at 2am).

To the Editor,

My husband "John" has been diagnosed with mild hepatitis C. Following his liver biopsy, our doctor was quite surprised to find he only has mild hep C, as his liver function tests supposedly showed different.

We were quite shocked when he told us John was eligible for Interferon, but didn't know anything much about the side effects or other treatment possibilities. We are going to change our doctor as we found it insensitive when he was amused that John, who used needles 15 years ago, was very hesitant towards using Interferon injections.

I want to try to get as much information as I can about Interferon drug treatment.

Can anyone who has had the treatment please write to me and tell me what it was like. You can address your letters to MM, c/- Hepatitis C Council of NSW (postal address on page 3).

Regards, MM

To the Editor,

I take an active interest in national politics and was recently drawn to a hepatitis C related question put in the Federal Parliament's Upper House.

Senator John Herron (a Liberal Senator from QLD), asked Senator Rosemary Crowley (Labor Senator from SA) why there was a delay in the implementation of the National Hepatitis C Action Plan relating to the availability of Interferon treatment in the Australian Capital Territory.

In responding to the question, Senator Crowley stated that the Commonwealth, in allocating $1.9mill annually over a two year period, had met its responsibilities under the Action Plan in relation to national education and improving national surveillance activities.

I am surprised that hepatitis C funding rates so low in comparison to other disease conditions ($110mill - HIV,).

I would like to know if Carmen Lawrence and her Commonwealth Department have any responsibilities to assisting with information, care and support for people who already have HCV? Apparently these aims are well documented in the National Hepatitis C Action Plan.

Yours sincerely, MG

We shall forward a copy of your letter to Dr Lawrence and hopefully be able to publish a response in the next edition - Ed.

Hep C in prison - a D&A worker's perspective

During the 3 years that I have been involved in Corrective Services I have seen an ever increasing number of inmates with the hepatitis C virus.

As a Drug & Alcohol worker I am of course concerned about the transmission of the virus via the sharing of needles and unsafe sex practices, and other issues such as the high fat diet found in prisons and the erratic implementation of Departmental policy on the easy availability of bleach for inmate use.

The development of effective policies which respect the rights and safety of all concerned are of paramount importance - equally important though is finding ways to get these policies implemented in all areas of all prisons and to meaningfully educate staff and inmates about their significance. An adequate, rather than a bare minimum of expert educators, D&A workers and medical staff would seem useful as well given the size of the problem.

Of particular concern to me as a counsellor, is the psychological impact of receiving an HCV+ diagnosis whilst in prison and the ways in which people strive to come to terms with HCV and continue their lives. Receiving an HCV+ diagnosis is for many, tantamount to being told they have a life-threatening disease. This is hard enough to bear in the general community where there are friends, family and access to a wide range of treatments, information and support, but is anguishing within prison where inmates may not receive the immediate emotional support, information and medical expertise which many people need at such a time.

Other inmates and staff may not bother to hide their contempt for the HCV+ inmate. Worst of all, inmates are away from the people that love them and whose lives may also be changed by the diagnosis. Imagine telling your partner in a crowded visiting area that you are hepatitis C positive.

"The development of effective policies which respect the rights and safety of all concerned are of paramount importance"

An inmate's reactions to an HCV+ diagnosis are the same as anyone else - shock, grief, fear, hopelessness, anger, remorse, shame, feelings of deep worthlessness and futility and denial. Prison is a harsh and stressful emotional environment in which to live in the best of times, and emotional vulnerability can be a liability in terms of survival. Small wonder that some inmates avoid testing in order to live in ignorance. Denial, fear and a feeling of powerlessness can lead to increased drug use and needle sharing. In the long-term this can lead to an inmate who is even more unhealthy both physically and emotionally. Of course, increased injecting drug use will also lead to further transmission of HCV and other viruses.

A very small percentage of long-term inmates may, in time, die in prison from the virus - not an easy thing to come to terms with. The majority of inmates simply try to get on with life the best way they can - often minimising or denying their concerns. A precious few use diagnosis of the virus to assess their lives and make significant changes to their drug use and general health. Diagnosis is a turning point for these inmates and life takes on a new value.

It therefore seems to me important that all staff and inmate peer educators that deal with HCV+ inmates are familiar with the dynamics that surround life-threatening illnesses and that prison managers begin to recognise the psychological impact that diagnosis may be having on

(Continued on page 9)

Farewell Rod & Richard

Our committee recently lost two hard working members - Richard Booker and Rod Charls - although both remain ongoing Council members.

Richard, a committee member since the Council formed, back in September 1992, was our inaugural Vice-President. He has continued to provide valuable input into our Council, especially in the area of advice on computing and allied technology.

Rod joined us in March 1994, following his facilitation of a committee skills development program for us. Rod was soon a Committee member where his valuable political skills and knowledge of health policy and bureaucratic process have served us all well - Rod played a pivotal role in our protracted funding negotiations with the previous Health Minister, Ron Phillips.

We extend our best wishes to Richard and Rod, and a warm thank-you for all their energy and involvement.

UNIQUE NEW INTERFERON TRIAL

A new clinical study that aims to provide greater information and understanding of the hepatitis C virus and its response to treatment with Interferon is currently enroling patients.

Sponsored by Roche Products, the clinical study called Aushep 04 aims to further expand our knowledge of the hepatitis C virus.

AusHep 04 will closely examine whether the response to Interferon is affected by:

- the amount of virus present,
- duration of Interferon treatment, and
- viral genotype (subtype).

Associate Professor Frank Dudley, Director of the Gastroenterology Department at the Alfred Hospital in Melbourne and principle investigator of the study, says that Aushep 04 will greatly increase our knowledge of the viral factors that influence how hepatitis C virus affects Australian people. The study may be valuable for the further development of effective treatments.

He went on to say that, "people entering the study will have the opportunity to be selected for 12 months treatment with Interferon." Presently the Pharmaceutical Benefits Scheme only funds treatment for 6 months but there is increasing evidence that suggests 12 months therapy may be superior."

In addition, participants in the study will undergo PCR tests at regular intervals to determine the presence, amount and subtype of virus circulating in their blood. These tests will provide valuable information that will help us understand why some individuals have a poorer outcome of infection and don't respond as well to Interferon treatment.

People entered into the study will need to satisfy a series of selection criteria which include:

- no previous treatment with Interferon,
- positive antibodies to HCV,
- liver enzymes 1.5 times the upper normal limit,
- non-cirrhotic, and
- confirmed presence of HCV.

As well as a potential 12 month treatment period, all participants will receive close monitoring and care, with 12 months additional follow up to determine the long-term benefits of treatment.

In NSW, Aushep 04 is being conducted at RPA, Concord, Liverpool and Westmead hospitals.

Discuss this article with your General Practitioner if you feel you fit the criteria and want to enrol.

For more info, contact the Hepatitis C Council of NSW on 02 332 1853 and ask for information on the Aushep 04 trial.

NEW SOUTH WALES

MINISTER FOR CORRECTIVE SERVICES AND MINISTER FOR EMERGENCY SERVICES

STATEMENT FROM BOB DEBUS, MINISTER FOR CORRECTIVE SERVICES.

Hepatitis C has been an area of neglect for some years.

Voluntary testing for HCV is carried out in NSW prisons. However as it is not mandatory, figures vary wildly on just how many people in our gaols have the virus. It is significant to say that as the prison system contains many people who have injected drugs regularly, it can be assumed the HCV rate is high.

That being recognised, a number of practical steps are being taken to ensure that the rate of infection does not increase within the system.

Cabinet has recently approved a trial of condoms in prisons. Negotiations to work out how condoms will be distributed, to whom and just as importantly, how they will be disposed of, are currently underway.

The Department of Corrective Services' Research Unit is currently working on a major evaluation of the effectiveness of current control programs being run in gaols.

Peer education and training and information sessions along with extensive printed and video information are playing an important role in inmate education on all communicable diseases. In fact the Prisons AIDS Project [recently renamed the HIV & Health Promotions Unit] has recently been expanded to include all forms of hepatitis and tuberculosis.

I expect to be able to provide you with a more detailed response to the problem of hepatitis C sufferers in the prison system when the Department's research project is completed early next year.

In the meanwhile I would welcome any submissions from the Hepatitis C Council of NSW and indeed, the readers of the *Hep C Review* on this issue.

Bob Debus M.P.

Postal Address: GPO Box 31, Sydney NSW 2001

HEPATITIS C - the new health threat

Just as we appear to have succeeded in slowing the spread of HIV, attention has been drawn to our failure to contain and manage hepatitis C. This condition, identified in 1989, attacks the liver and is thought to involve 9,000 new infections a year. It has become the most common cause for liver transplants.

Health authorities, under-resourced and complaining of a slow political response, are crying out for assistance to combat this disease, in terms of both preventative education and the treatment and care of patients.

What makes hepatitis C so difficult to contain is that many people who have been presenting with symptoms could have acquired the virus 10 or even 20 years ago. As many as 200,000 Australians may have the virus.

The mortality rate of HCV is around 7%. This means the number of deaths from HCV will be approximately 14,000 - over 3 times more than the number who have died of HIV/AIDS (just over 4,000 at the end of 1994).

We need to learn more about hepatitis C and how it is spread. It may be that people who experimented with injectable drugs but have since developed otherwise healthy, drug-free lifestyles, could unknowingly have HCV infection. Also, there is speculation that the fashion for tattoos and body piercing, or even the shared use of razors or toothbrushes, may have contributed to the spread of the infection.

One year into a national strategy on hepatitis C, a federal review shows how slight the progress has been. The Federal Government has allocated less than $4 million over two years to fund surveillance, care, education and prevention. Community awareness campaigns are to begin soon. But the rapid spread of infection has caught the authorities napping.

Queues have formed among diagnosed patients [up to 6 months in some NSW treatment centres] competing for treatment with the drug Interferon. Many others appear to be caught in an intolerable log jam while they wait for their condition to be assessed.

Taking a national focus is the right move but it has been slow to get under way. Also, compared with funding for other health programs, the financial priority attached to hepatitis C is too low.

The nation must get its strategy right. But there is no time to lose.

An abridged version of The Australian newspaper Editorial, Mon 23 October 1995.

Gaol Ink - a prison tattoo project

Since the dawn of time, people have adorned their bodies with jewellery, clothes and tribal/cultural tattoos or scarring. To the English speaking world the tattoo was introduced by sailors who collected the mystical and colourful designs from exotic eastern ports so that their bodies could be identified in case of shipwreck or misadventure.

Tattoos have evolved throughout time to become the art form they are today. Worn as totems of strength, religion, love and devotion, the tattoo brings out different feelings in each of us. To some of us they are mystic markings of the rights to life's passage, to others they are signs of ruffians with criminal tendencies.

People either love them or hate them. If you intend to have an indelible piece of art placed upon your body then you have a lot of things to consider - especially if you are in gaol.

Recent research has shown that only 7% of inmates believe that HIV or hepatitis can be contracted through tattooing - this means that 93% of inmates are unaware of the risks of bloodborne communicable disease. It is also alarming that around 40% of the gaol population are hepatitis C positive.

In early 1995 the HIV & Health Promotions Unit, in conjunction with other major departments outlined strategies to reduce the level of unsafe tattooing in correctional centres. At this time I was still working in institutions and seeing a lot of beautiful tattoo designs being confiscated and a lot of ugly (and dirty) gaol style tattoos being done.

After contacting the HIV & Health Promotions Unit Manager, Gino Vumbaca and the PTAA (Professional Tattoo Association of Australia), the Gaol Ink project was born. The aim of this project is to give inmates an avenue to achieve recognition and receive rewards for their work, and of course, to educate on the hazards and risks involved with gaol tattoos.

One of the major criteria in getting a tattoo that you will love forever (because that's how long you'll have it) is being careful. Careful about who does your tattoo, what your tattoo is of and where you get it. Being in gaol you don't have many choices.

Recently the Department of Corrective Services has approved a tattoo project for inmates. This project includes tattoo design competitions and offers

(Continued on page 13)

Hep C in prison - a D&A worker's perspective .. continued

(Continued from page 6)

their inmates along with being familiar with practical information about how the virus affects people physically.

Treatment options apart from Interferon need to be developed for both cost and practical reasons. People on Interferon need careful monitoring and a good deal of support - not an easy task in a prison setting where staff are generally stressed and overloaded. Interferon is not suitable for everyone and many inmates would not meet the patient eligibility criteria developed by the Commonwealth last year. These criteria exclude people who inject drugs, people who have a history of significant psychiatric problems and those people who are also HIV positive - that is, a large proportion of people in prison. The needs of long-term inmates in particular need to be addressed. These inmates are incarcerated for many, many years and while in prison need access to what would be available to them in the community.

It is heartening that myself and an inmate have been able to run a voluntary project which explores alternative/complementary treatment for HCV+ people. This project has been attended by Corrections Health staff and representatives from non-uniformed and custodial staff. We hope that the videos of the talks by alternative and complementary practitioners will eventually be available to inmates in all prisons and we are grateful to the HIV & Health Promotion Unit for funding the resources needed for this project.

All of the complementary and alternative treatments encourage people to take an active part in their own health management, and not be passive recipients of any particular "treatment".

This is significant for disempowered and institutionalised individuals who can easily fall into a victim mentality. We hope that the most significant outcome of the project will be that Corrections Health will actually evaluate these treatments. If the treatments are found to be worthwhile, we hope they will set up clinics for inmates. I imagine this will be a long way down the track.

Also heartening is the "in principle" acceptance and funding by the Drug & Alcohol head office of a program proposal to trial a group at Long Bay aimed at helping inmates come to terms with having a life-threatening illness and develop self care strategies on all levels of being. This program will provide inmates with a level of information, education and support similar to that which they would receive in the general community, and will strongly encourage inmates to take as much responsibility as possible for promoting their own well being.

a report by Deborah Martin-Smith

How can I make a difference?

By filling out and returning the Powell-McDermott survey form that was contained in the Hep C Review, edition 12.

If you want a copy, just phone the office.

By taking part in the Bond University research project - involving a 30 minute interview that would be held at the Council office. Interviews would be during the week or on the weekend.

Both these projects will provide valuable information that will help us lobby for more resources and the better planning for hepatitis C services for people affected - phone Paul on 02 332 1853.

You are also invited to come into the office or phone at any time to discuss the wide range of volunteer work available.

See page 20 for more information.

PRISONS & HCV - the community policy

Prisoners have been identified of significant risk of transmission of blood borne communicable diseases, particularly hepatitis B (HBV), hepatitis C (HCV) and HIV.

Rapid spread of infection in prisons is more likely than in the general community due to the combined effect of pre-existing levels of infection with low access to the means of prevention against transmision.

In response, a coalition of community-based organisations, including the Hepatitis C Council of NSW, have developed and launched an extensive policy on Prisons and Blood Borne Communicable Diseases. Other community organisations to adopt or endorse the policy include:

- Prisoners Action Group,
- Justice Action,
- AIDS Council of NSW,
- NSW Users and AIDS Association,
- Gender Centre,
- National Centre for HIV Social Research,
- Council for Civil Liberties,
- Aboriginal Deaths in Custody Watch Committee, and the
- Redfern Legal Centre Drug Law Reform Project.

The policy deals with sensitive items that need immediate implementation to prevent the spread of blood borne communicable diseases, and to better facilitate more than just adequate care and treatment of positive prisoners.

The shortfalls of the NSW prison system have major ramifications for the entire community, particularly given that most prison sentences are short-term.

A recent study of Victorian prison entrants by Crofts et al found that 39 percent of prisoners were HCV positive and 0.4 percent HIV positive. A recently completed NSW study supports the findings of the Victorian study.

With such massive infection rates compared to the overall population, the urgency for reform becomes glaringly evident.

"39% of prisoners were HCV positive"

While there is strong commitment in the general community towards harm reduction measures such as needle and syringe exchange, methadone maintenance and peer education, there are few such programs in Australian prisons, even though promotion of safer behaviour is more likely to be effective than attempted suppression of risky behaviour.

(Continued on page 17)

New hepatitis clinic at Long Bay Gaol

Although detailed estimates of the prevalence of hepatitis C (and B) in inmates of NSW prisons have not been published, limited surveys suggest that a substantial proportion of all new prisoners are sero-positive for hepatitis C or B (or both).

Prisoners interred for drug-related crimes appear to carry a prevalence of hepatitis C infection similar to that of the general injecting drug user population, of approximately 70%. Sharing of injecting apparatus for illicit intravenous drug use undoubtedly occurs within the prisons, but at an unknown frequency. The average length of stay in the NSW prisons is just over 7 months.

Given this background, it is unequivocally clear that prisons are likely to be an important site of transmission of blood borne infections, notably hepatitis C, and of subsequent transmission within the general community. Accordingly, a specialist medical clinic has been established at Long Bay Gaol Complex to provide education and medical assessment for inmates of NSW prisons. Research activities are also an important planned component of the clinic activities. The clinic is staffed by an Infectious Diseases physician, and a Gastroenterologist from the South Eastern Sydney Area Health Service, in conjunction with nursing staff from the Corrections Health Service. Referrals are accepted of any inmate who is hepatitis C positive or hepatitis B surface antigen positive ***and*** who has repeatedly abnormal liver function tests. These biochemical tests are initiated by the Corrections Health Nursing team after the detection of initial sero-positive results from voluntary screening at entry (or at any time thereafter).

Approval has been obtained for provision of Interferon therapy for highly selected cases of chronic hepatitis C or B under the S100 scheme. Consequently, a facility has been established to undertake liver biopsies in the hospital at Long Bay Gaol. Potential candidates for therapy are scrutinised not only along the standard lines, but also have psychiatric as well as Drug and Alcohol evaluations. With the vast number of potential referrals the clinic has restricted its focus in the first 6 months of operations, to inmates predominantly from Long Bay Gaol, although referrals from throughout the NSW prisons system are accepted.

Associate Professor Andrew Lloyd - Corrections Health Service

Hepatitis C at epidemic proportions

Hepatitis C has reached epidemic levels among injecting drug users, with a national survey revealing more than 50% are HCV antibody positive while only about 3 per cent of those surveyed tested positive for HIV.

"Consideration will need to be given to developing more effective methods of reducing the population at risk," the suvey reported.

"Is it possible to facilitate a transition from injecting to non-injecting routes of administration to reduce the incidence of serious complications such as overdose and hepatitis C? This is a question we should not postpone."

Hepatitis C is transmitted through contact with blood and is a "sleeper" disease, taking an average 13 years to exhibit systems which can be quite mild or as serious as cirrhosis, liver failure and liver cancer.

The national coordinator of the study, Dr Wendy Loxley, said the riskiest behaviour in contracting the virus, sharing needles, have been declining steadily, with only 3.8 per cent reporting they had shared a needle.

But Dr Loxley said the high incidence of hepatitis C antibodies indicated any blood-to-blood contact, even as minor as sharing a drug tourniquet where blood had dropped, would transmit the virus.

"It's the sharing of any kind of injecting equipment that could transmit the virus, it might be from casual blood contact... just one small drop," she said.

But Dr Loxley emphasised that hepatitis C was not confined to current drug users; anybody who had shared a needle could carry the virus.

"There are a lot of very ordinary suburban people holding jobs and leading normal lives who may have injected once or twice 20 years ago and might be infected with hepatitis C."

"the response by the government to the virus had been inadequate"

The executive officer of the Hepatitis C Council of NSW, Mr Stuart Loveday estimated 100,000 to 200,000 people in Australia were infected with hepatitis C, with between 7000 and 9000 new infections every year.

"Death from HCV is quite low, about 5 to 10 per cent, but in terms of sickness, more than 60 per cent of people will experience some negative effect - with a high cost to the community," he said.

Mr Loveday said the response by government to the virus had been inadequate, with the national strategy on hepatitis C allocated only $3.8 million over two years to cover surveillance, education and prevention.

The survey of 872 injecting drug users found 55 per cent carried antibodies to hepatitis C virus while almost one in five had been exposed to hepatitis B.

Abridged from Justine Ferrari's article in The Australian - 18/10/95

Paul Harvey, about to deliver ten thousand of our new Hepatitis C brochures to Darlinghurst Post Office.

Following development of our new brochure *Hepatitis C - a brief introduction*, we have initiated a distribution campaign that covers the state.

We have sent brochures to all divisional representatives of GPs across NSW. Of the 38 GP reps, a quarter have replied and requested a total of 2,000 brochures, each to be sent to a GP. In time, all doctors across the state will be sent one of our brochures and an accompanying order form.

Our Council's professional and organisational members were recently sent brochures and order forms and have so far purchased over 35,000 brochures.

Soon we shall be distributing the brochures throughout the networks of community and hospital pharmacists.

We are very grateful to ***Breakout Press***, who in doing their bit for the hepatitis C response are printing our brochures at cost price.

Specialists denounce HCV strategy

One year after the adoption of a national strategy on hepatitis C, a federal report reveals little progress on its implementation and concerns about limited resources and services, triggering criticism by medical specialists and hepatitis C support groups.

A progress report by the working group of the Australian Health Ministers Advisory Council (AHMAC) this month shows policies for the treatment of patients and education programs are still being developed.

The report also includes updates from the States and Territories, many of which report that funding restraints are inhibiting compliance with the national action plan while existing services are stretched.

"Constraints experienced in this area of service delivery (management and treatment) include insufficient services at teaching hospitals to meet the demand for hepatitis C assessment and treatment," the West Australia update says.

In the ACT, about 100 people were waiting for the only treatment, the drug Interferon, while a possible 1500 required assessment for treatment.

"It appears that this is due to the lack of funding for the management and treatment of hepatitis C," it says.

The Federal Government made the first specific funding allocation for hepatitis C in the last Budget, allocating $3.8 million over two years, following the endorsement of the national action plan last October by AHMAC.

"I can understand people saying it isn't moving quickly enough but we've got to get it right and we need to make it nationally consistent," a spokeswoman for the federal Health Department said.

But hepatitis C support groups and medical specialists yesterday criticised the government response for being too slow, following the identification of the virus in 1989, and providing insufficient resources.

The Storr professor of hepatic medicine at Sydney University, Professor Geoff Farrell, said the waiting list for his liver clinic at Westmead Hospital was six months.

"I think the major single problem for hepatitis C patients at the moment is getting access to services where they can get appropriate counselling and treatment. There's a dearth of centres," he said.

Professor Farrell, who was instrumental in the formation of the first hepatitis C support group in 1991, said the epidemic had progressed more rapidly than anticipated, with liver cancer at least doubling over the past decade because of the virus and hepatitis C becoming the most common cause of liver transplant over the past 12 months.

Abgidged from Justine Ferrari's article in The Australian newspaper 21/10/95.

Membership

Most Council members' 1996 fees are due by 1 March. Please forward your fees as soon as possible.

To help maintain our records, please complete both sides of the membership form on page 32 and return it with your payment. If you have any difficulties with the form, just phone the office and ask for Prue (332 1853).

If you are in financial hardship and membership fees are a problem, don't worry - contact Paul or Stuart.

HCV BOXERS kicked out of the ring

Four Victorian kickboxers have lost their licences after testing positive to hepatitis C. From 1 July 1995, Victorian boxers and kickboxers have undergone blood tests for HIV and hepatitis C and B. Boxers who test positive have their licences to fight withdrawn.

Ring-side physician Dr Peter Lewis said that all contestants in Victoria had been tested since the Victorian Department of Health had initiated the tests. "We do not think its particularly caused by kickboxing," Dr Lewis said. "Fighters are not transmitting it to each other."

Dr Lewis said that no Victorian fighters had tested positive for HIV. "In Australia my strongest belief is that it will not be HIV or hepatitis B we have to worry about - its hepatitis C."

The Victorian regulations were put in place following the success of NSW initiatives in place since 1989. This involved the Department of Sport, the Boxing Authority of NSW and the industry coming together to discuss the need for protective measures and agreeing unanimously on a program of 6 monthly tests for all contestants.

NSW boxing referees must wear surgical gloves for protection and it is recommended that 'corner people' - the contestants support teams - have regular HCV tests done as well.

Adapted from Michael Alexander's article in HIV/AIDS Legal Link 3/9/95.

THE INSIDE STORY - Law & NSW prisons

BAIL AND COURT

Bail is an agreement to return to court at a later stage, to answer a criminal charge. If bail is not obtained, the person charged is held in custody on remand.

Summary Offences are common minor offences and are dealt with at Local Courts. These usually lead to fines, good behaviour bonds, community service orders, or imprisonment.

Indictable Offences are serious offences including murder, drug trafficking, sexual assault, arson, perjury, bigamy, theft (greater than $15,000) and malicious wounding. These offences are dealt with in *District Courts* or the *Supreme Court* after a committal hearing in a *Local Court*.

SENTENCING & PAROLE

Prisoners are held in the custody of the Governor of the gaol. All prisoners are subject to the general laws of the land and the Prisons Act.

Fixed Terms involve sentences of less than 6 months.

Minimum & Additional terms involve sentences of 6 months and greater. These involve a set non-parole term, called the *Minimum* (usually no less than 3/4 of an overall sentence), and the remainder which is called the *Additional*.

A **life sentence** for prisoners sentenced after 1989 means life. Life prisoners sentenced prior to 1989 can apply to the NSW Supreme Court for a Minimum & Additional sentence.

Parole for prisoners with a total sentence of 3 years or less is automatic. If longer, parole must be granted by the Offenders Review Board.

NSW PRISON SYSTEM

The Department of Corrective Services controls approx 25 institutions ranging from maximum security prisons to open farms and forestry camps.

Women are held at Emu Plains, Mulawa & Norma Parker Correctional Centres.

Recent amendments to the Prisons Act allow private corporations to operate and manage prisons such as the Junee Correctional Centre.

PRISON POPULATIONS

In 1994, there were approx 6,300 NSW prisoners. Of these, 77% were serving sentences and 23% were on remand.

The typical prisoner is a single Australian-born male, unemployed when arrested, and between 20-30 years old. He has no formal educa-

(Continued on page 14)

Gaol Ink - a prison tattoo project .. continued

(Continued from page 8)

This project has gained the full support of the Professional Tattooists Association of Australia (PTAA) and the respected tattoo magazine, *Live to Ride.*

Having your tattoo done with an unclean, gaol-made tattoo gun places you at great risk of infection because the person who was tattooed before you may well have hepatitis C, hepatitis B or HIV. The people who were tattooed before you may not even know whether they have these infections or not. Obviously it is safer to give it a miss.

Graphic reprinted courtesy of NSW Users and AIDS Association (NUAA) and Bikers' Tribes Project.

It is safer to wait until you get out and then get a clean, beautifully coloured tattoo that you will be proud of. If you can't wait, then ensure you make it a clean one.

Look for the pamphlets with the *"THINK BEFORE YOU INK"* slogan. These contain information about making tattooing as clean as possible and minimising the chance of infection or transmission of diseases. These pamphlets will be available in January 1996.

If inmates have designs or drawings that you intend to ink, then wait. Enter them in the competitions that are coming up. Look for the Design Competition Pamphlet and remember - designs must be on the official entry forms.

For further information, phone the HIV & Health Promotion Unit, Tattoo Project Officer 'Terri' on 02 289 1293.

Law & NSW prisons .. continued

(Continued from page 13)

tional qualifications, has a literacy problem, has previously served time in prison and has a criminal record of approx 25 convictions.

The typical prisoner has a dysfunctional family background with a history of sexual abuse, is under medical treatment and has a history of drug and/or alcohol abuse.

Specifically, **95%** of NSW prisoners are male,
59% were unemployed when arrested,
13% were pensioners when arrested,
8% are Aboriginal,
84% have a non-English speaking background (Lebanon, Yugoslavia, Italy, Vietnam),
25-29 is the most common age,
6% completed secondary education,
22% have a history of significant psychiatric hospitalisation or treatment,
13% have a significant intellectual disability or are borderline,
49% admit to drug problems, and
18% admit to alcohol problems.

Crimes involved are typically 33% against property or 33% against persons.

Common convictions involve

theft	40%
robbery	12%
drugs	11%
homicide	8%
sexual assault	7%
driving	7%

ENTERING PRISON

At reception, prisoners are searched, certain personal possessions are confiscated and prison clothes are issued. A medical assessment is made and the prisoner has an interview with the prison welfare officer & prison committee.

Prisoners who are also parents should be told of their rights which include attending Family Court in regard to their children's care. Here, the prisoner must notify the court which will issue an order allowing him/her to attend. Other rights include receiving visits from children and recovering care & control of them upon release.

Classification: prisoners will have been classified as
A1 or A2 - maximum security (barriers with towers)
B - medium security (barriers)
C1, C2, C3 - low security (no barriers or constant supervision)
E1, E2 - prisoners who have previously escaped (must remain A1, A2)

A *Program Review Committee* can reclassify prisoners except for serious offenders.

The *Serious Offenders Review Board* can reclassify life sentenced prisoners, or those serving 12 years or more.

SEGREGATION

Segregation of prisoners is an option of the Governor. It is able to be authorised in short term cases by the Governor, and for periods greater than 3 months by Commissioner with a right of appeal to the Serious Offenders Review Council. Segregation can also be ordered or requested if the prisoner is deemed in danger. Segregation programs exist to keep young first offenders and young developmentally delayed prisoners away from general prison population.

TRANSFERS

Transfers cannot be made without authorisation of the Commissioner. In practice, though, prisoners are often moved, invariably without proper orders.

(Continued on page 15)

Newcastle herbal treatment trial

The CH-100 trial has progressed very encouragingly over the past few months. Almost 60 patients have been registered and over 20 of these have now completed therapy. Side effects have been few and most patients have completed their treatment without major problems.

A number of patients who have finished the trial have gone on to further herbal preparations in their desire to maintain the perceived improvement they experienced during the trial. Those patients who have received placebo (a harmless substitute for the real treatment), who wish to try the actual preparation have been allowed to commence the CH-100.

At this stage, there has been no analysis of the results as we have to have the full group of 60 patients complete therapy (this will occur early this year).

There is growing interest in this approach to therapy, particularly as research centres in China are now evaluating the treatment using PCR studies for viral eradication.

All patients completing treatment in our trial are being PCR tested for hepatitis C RNA (the part of the virus detected by PCR).

Our plan on completion of this trial is to move to a modified protocol allowing variation of the dose according to the clinician's assessment.

These are exciting times. Thanks to all those who have helped this trial run so smoothly.

Regards, Prof Bob Batey
John Hunter Hospital, Newcastle

Law & NSW prisons .. continued

GAOL SERVICES

Medical Services are delivered by the Corrections Health Service, a part of NSW Health. Serious cases are dealt with by Long Bay Prison Hospital or Prince Henry Hospital. Corrections Health Service also have psychiatric nurses and psychiatrists, a Crisis Support Unit (at Goulburn), and a Crisis Intervention Unit (at Long Bay).

Women can access prenatal and antenatal services, and some can serve with their children.

Major problems exist in relation to drug & alcohol use. For example, there is no detoxification unit at Mulawa, and only two D&A counsellors for the entire prison.

Education programs are currently accessed by 20% of prisoners. Typically, these include literacy, elementary skills & job training. TAFE & University correspondence courses exist as do developmentally delayed programs within the *Developmental Units* at Goulburn (12), and Mulawa (6).

The department has recently introduced a new educational program called AEVTI - the Adult Education & Vocational Training Institute. This program is specifically designed for inmates but there is concern that it may limit the availability of TAFE courses, resulting in a loss of flexibility for educational programs as a whole.

Employment programs involve 50% of prisoners. The work includes manufacturing, printing, kitchenwork, sweeping, cleaning, prison farm work and forestry. The pay is well below award rates except for the 100 prisoners on work release who get award or better. Those unwilling to work get no allowance. Those willing, yet unemployed, get $9 per week. Safety standards are regulated by the Occupational Health & Safety Act, and the Factories, Shops & Industries Act.

Mail is unlimited, to and from a prisoner's lawyer. Such mail can be marked confidential, sealed in an envelope and sent with a cover letter to the Governor. All other mail is limited and can be opened and examined.

Phone calls are limited to a set amount per week.

Home visits to attend funerals or visit seriously ill close relatives are often permitted. Prisoners are usually escorted by prison officers.

Legal Assistance is available through the *Prisoners Legal Service* which can deal with life sentence re-determination hearings, parole hearings, charges for prison offences and classification problems.

Prisoners often experience difficulties obtaining access to information and legal services. They are not legally represented when facing internal disciplinary measures, including transfers to other prisons. It should be noted that in the past, visiting Justices heard certain disciplinary proceedings and prisoners were represented - procedures that no longer exist.

RELEASE SERVICES

Gate money is paid at 30c per week, up to $100 for sentences less than 7yrs, and $150 for sentences greater than 7yrs.

A **special gratuity** of $200 can be paid at the discretion of Governor.

(Continued on page 16)

Hepatitis C Council of NSW - AGM

We held our Annual General Meeting at 7pm on Thursday evening, 26 October. Cheryl Burman, chaired the meeting with our retiring 1995 Secretary, Richard Booker, serving as Electoral Officer.

Although feisty debate surrounded the motion to accept the special resolution implementing the proposed new constitution, the motion was passed almost unanimously. Our Council now operates under the new constitution. (See page 25)

The election of 1996 office-bearers saw a mix of new and previous faces. Shown above, are Jennifer Holmes (V/President) and Cheryl Burman (President), seated L-R; and Stuart Loveday, Rod Bennison, John MacKenzie (Secretary), and Leone Robertshaw. Absent are Anita Long (Treasurer) and Bernard Fischer.

Law & NSW prisons .. continued

(Continued from page 15)

An **Employment Development Scheme** lists employers willing to employ ex-prisoners.

Civil Rehabilitation Committees can assist with pre-release information and accommodation and/or employment on release.

The **Prisoners Aid Association** may provide financial assistance, food vouchers, storage of property.

Halfway Houses often provide accommodation for male or female ex-prisoners.

It should be noted that in general, there are insufficient pre and post release transition services. Prisoners are not properly prepared for their release back into society and there is a need for further ex-inmate support programs.

PRISONER'S KEY ISSUES

- Instability of custody due to repeated transfers which often disrupt family contact and add to psychological trauma.
- Poor ongoing access to support systems, such as partners, family and relatives.
- Limited access to methadone programs & harm minimisation services.
- Limited access to medical and psychiatric services which are taken for granted within general community.
- Seriously high level of hepatitis C infection (35-40%) in prisons, as opposed to general community (<1%).
- Limited access to vocational, educational & life skills training aimed at breaking the high return rate.

Adapted from *The Law Handbook* 5th Edition 1995 (published by Redfern Legal Centre Publishing) with assistance from Justice Action and the Prisons Legal Service.

International Prison Watch

NSW Report - prepared by Justice Action

NSW STATE COORDINATORS REPORT - 1995

Unfortunately in Australia, populist law and order campaigning is now the model for winning State government elections. During the March 1995 campaign the NSW Labor leader, Bob Carr, positioned his party to the right of the Liberal and National Coalition on criminal justice policy.

Under the reactionary regime of former Liberal prison minister, Michael Yabsley, the US industrial model for prisons was implemented, negating many of the reforms introduced following the Nagle Royal Commission. Following resistance from prisoners, and the political demise of Yabsley, some reforms have been reintroduced.

The most pressing issues have been identified as:

PRISONS OVERCROWDING & REMISSIONS

All NSW prisons are greatly overcrowded. The prison population has increased from 4,691 in 1988 to 7,100 in 1995. The Aboriginal population has increased from 369 in 1989 to 901, a rise of 154%.

Overcrowding problems include:

- shared cells
- early lock-ups, and
- weekends spent in small crowded yards.

Existing services are overstretched as a consequence.

The overcrowding is due largely to the "Sentencing Act 1989", referred to as the Truth in Sentencing legislation, which has extended the length of sentences served, reduced the time spent under community based parole, and

(Continued on page 23)

LIVER BIOPSY - what is it?

Liver biopsies are sometimes recommended by specialists and are the best way of determining the condition of liver cells. After the skin is sterilised and an injection of local anaesthetic is given, a needle is passed between the ribs and into the liver and a small sample is taken for microscopic examination. Some doctors may do the procedure using an ultrasound machine to guide them.

For those people with blood clotting disorders, liver biopsies are not advised because of the risk of internal bleeding, but for most people, the procedure is relatively problem free.

Some people experience discomfort during or after the biopsy while others don't even realise it has been done. Local anaesthetic is always used, but if you are concerned, ask for some pain killing tablets and something to calm you down.

Following the procedure patients are asked to lie still for several hours so it is advisable to take a book or a personal radio-cassette.

The biopsy result describes in detail the condition of various parts of your liver, including individual types of liver cells. The result form will be given to you to take back to your GP. It can be useful to ask the specialist or your GP for a photocopy of your results to keep for your own personal records.

PRISONS & HCV - the community policy .. continued

(Continued from page 10)

Clearly, there is an urgent need to refocus harm reduction programs to ensure that prisoners are at no greater risk of contracting hepatitis C than people in the general community. This must apply while prisoners are inside or on transition from prison.

It is also vital that those harm reduction measures operating successfully in the wider community are not undermined through inferior infection controls operating within prisons.

A central theme of the community policy is the promotion of improved health and safety for everybody within prisons. Implementation of measures that effectively limit the transmission of blood-borne communicable diseases among prisoners are also in the best interests of staff.

For instance, operation of a needle exchange, on a strict exchange basis, will assist in decreasing the risks from needle stick injuries, protecting both prisoners and prison workers.

In contrast, the continued prohibition of syringes in prisons, ensures that syringes in prisons are continually reused, often until they wear out! Such chronic reuse substantially increases infection risks.

Decisive and courageous action is required from government if the community policy is to be implemented. Protecting the health of the community must take priority over current conservative inflexibility.

It's time to remind the creators of government policy that our society's respect for basic human rights, such as health, is best measured through its commitment to and compassion for society's marginalised populations. Prisoners are entitled to the same health services and protection from communicable diseases that are available to the rest of the community.

A report by John Mackenzie. (For copies of the policy or further information contact our office on 02 332 1853)

Present at the September policy launch were L-R, Brett Collins (Prisoners Action Group) Jan Cregan (National Centre HIV Social Research) Geoffrey Bloom (ACON) Camile Kersley (Gender Centre) Stuart Loveday (Hep C Council NSW) Chris Puplick (Anti-Discrimination Board) John MacKenzie (Hep C Council of NSW) Rod Bennison (NUAA).

NAT. epidemic - NAT. response .. continued

(Continued from page 1)

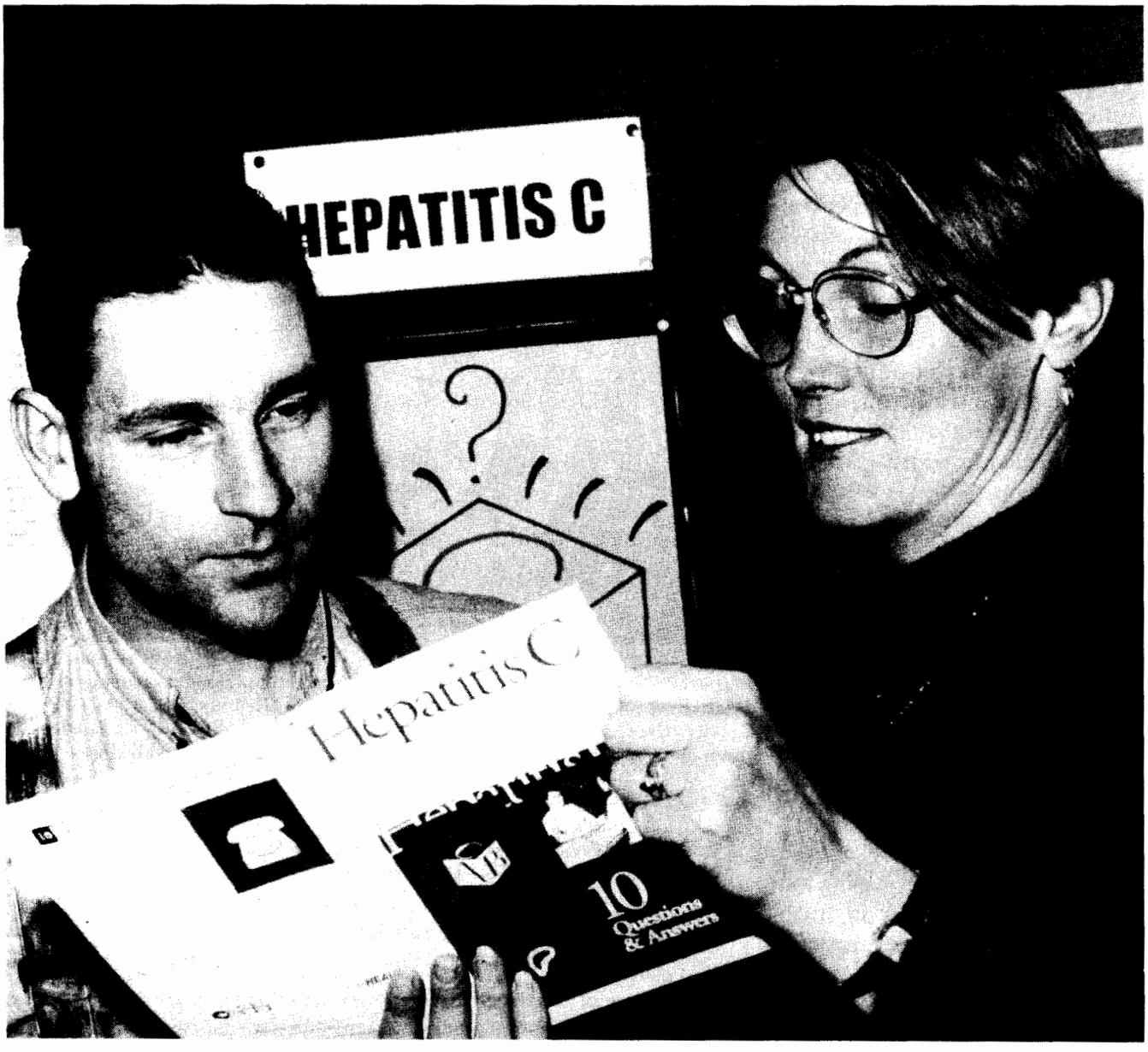
inject drugs (who experience the overwhelming majority of new hepatitis C infections) were represented by members of the Victorian injecting drug user group VIVAIDS and the national injecting drug user community group AIVL.

The formation of a national peak body was identified as a priority and became the focus of the evening. Participants agreed that a national peak body should be made up of the eight state-based hepatitis Councils and Foundations, and include a representative from AIVL - the national Injecting Drug Users' body. It was also acknowledged the body should liaise closely with people who contracted HCV through blood transfusion and products.

A national peak body would be responsible for ensuring effective communication between people with hep C and governments. It could also ensure state-to-state liaison regarding the various services provided by individual state groups. The proposed body would coordinate community representation on bureaucratic decision-making bodies such as AHMAC or NHMRC.

The participants agreed to take the above recommendations back to their respective organisations and seek formal endorsement of them. This having been achieved, each participating state body would delegate one representative to participate in a working group that could begin the process of formally developing a national body.

If you have any comments about the formation of a national body, please write in to your Council - other Council members would love to hear what you think.



(Picture above - republished courtesy of The Newcastle Herald)

Pictured above, is Melinda Fergusen-Finn, a committed volunteer and activist in the Hunter region, providing hepatitis C information at the Hepatitis C Awareness stand during a Newcastle University open day.

Pictured right, at the recent launch of the Prisons and Bloodborne Communicable Disease Community Policy is Brett Collins (Prisoners Action Group), Lis Kirkby (NSW Democrats), Stuart Loveday (Hepatitis C Council NSW) and Sarah Hopkins (Coordinator - Justice Action).

Brett is a hard working member of the Prisons Policy Working Group - the body that produced the Community policy.

Lis Kirkby is a keen supporter of your Council and has takes many opportunities to raise HCV-related concerns in her capacity as a Senator of the NSW Legislative Council, and on a national level through the Australian Democrats.

Hepatitis C within the prison walls

A special report by Tony Butler & Helen Taylor - NSW Health Department, AIDS & Infectious Diseases Branch

Surveys of prison inmates show high rates of hepatitis C and hepatitis B, the main reason for this probably being that a large proportion of prisoners have engaged in high risk behaviours - particularly injecting drug use.

Estimates suggest that up to 60% of inmates are imprisoned for drug related offences (NSW Correctional Health Service Strategic Plan) and a 1989 study estimated that between 25-45% of inmates were occasional users of injected drugs (Douglas et al).

Recent Victorian and NSW studies show that over 35% of inmates are hepatitis C antibody positive (Crofts et al, 1995) (Butler et al, unpublished). These studies also show that over 60% of inmates who report having injected drugs were positive for hepatitis C.

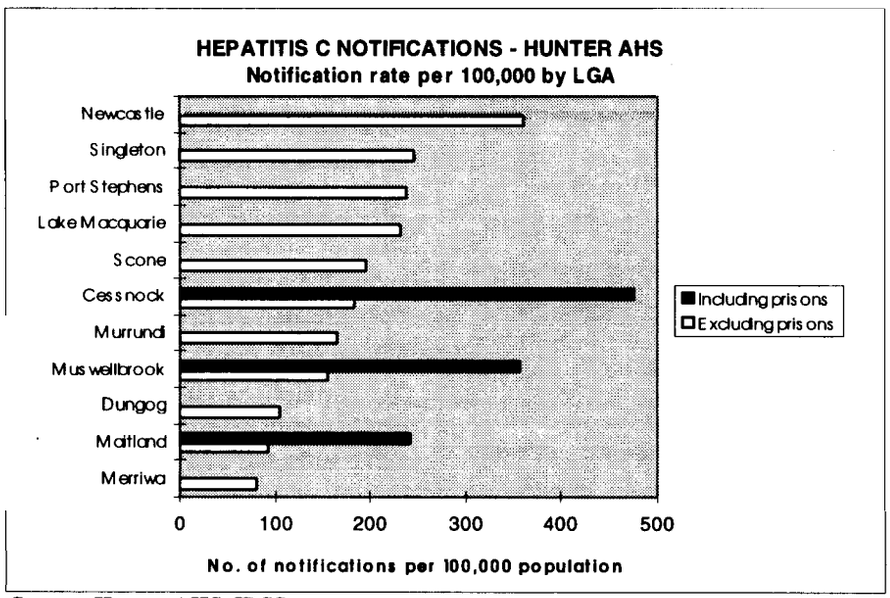
State Health Departments collect statistics on certain 'notifiable' diseases, including all types of hepatitis caused by viruses. This means that blood testing laboratories are obliged to notify the Health Department of every diagnosis of hepatitis C. Notification information is de-identified for statistical use by the department.

Notification data for HCV in the Hunter area were recently presented to a community meeting in Muswellbrook. People at the meeting were alarmed by the high number of HCV notifications in their local government area.

On closer examination of the data, however, it became apparent that the specific local government areas that had unusually high HCV notifications were where prisons are located (Cessnock, Maitland, Muswellbrook). As can be seen from the accompanying chart, notifications from correctional centres accounted for over half the total in the three Local Government Areas containing prisons, so the real rates of HCV notification in these communities were relatively low.

The lesson from this data is that notification figures for small local government areas may be distorted by the number of notifications arising from prisons and other facilities such as methadone treatment centres.

Any facility with large numbers of clientele who have used shared equipment for injecting drugs could distort hepatitis C notification figures. Notification data must be interpreted, therefore, with caution and with knowledge of the characteristics of a local government area.



Source: Hunter AHS, IDSS

GREETINGS FROM TAMWORTH - Country Music Capital of Australia

Firstly I would like to take some time to congratulate the executive staff of the Hepatitis C Council of NSW.

Apart from being extremely dedicated workers, they continue to provide me with as much information as they can about HCV and associated issues. They undertake their work with commitment and professionalism and ensure the Council provides a mouthpiece for the many NSW people affected with HCV.

BACK TO TAMWORTH

I have just returned after attending the 3rd National Symposium on Hepatitis C, and the Public Health Aspects of Hepatitis C Seminar, both held in Melbourne.

Two days of action packed information which will be of great benefit for our local community. I would like to thank the local Public Health Unit, the North West Health Service and Schering-Plough.

The Tamworth Hepatitis Support Group meets at the local Community Health Centre once a month. We provide individual and telephone support to people affected by the hepatitis C virus. Like most rural communities, isolation, confidentiality, discrimination and support are some of the difficulties that especially affect us.

We have found that attending a support group is not always the desired choice of people in the local area, so we feel that telephone support accesses many more people in our community.

We have planned to increase our Community Development work and are currently working with local government community services. Education programs, aimed at local healthcare workers, have occurred intermittently during 1995, and a stronger commitment will be made during 1996.

My professional capacity as a Drug and Alcohol worker has enabled me to provide information and counselling to the many people who inject drugs and attend the North West D&A Service.

Drug and Alcohol workers, along with workers within Needle and Syringe Exchange Programs, must show a commitment to providing HCV education and support to people who inject drugs. The epidemic is here and we must not be complacent in our response.

Margaret Gearin - Tamworth

"Want to help fight this epidemic?"

We certainly need more staff, there is no doubting that - both the paid and the unpaid variety!

Some types of work in the Council require specific staff who are here 8 hours a day, 5 days a week (executive staff, volunteer manager, receptionist, admin officer etc). Other work can be done by staff who come in on a casual basis. The table here shows types of work and whether staff need specific experience or if we offer special training.

The Council benefits greatly from people coming in to assist, but more importantly, we can provide benefits for you, the membership. We can enable you to meet other people and help thousands more. We can help you learn office and personal development skills that may assist you find casual/permanent work, or make life more enjoyable.

Most importantly, we can give you the means to take further control over this condition - one that too often can seem out of our control.

In regard to volunteerism, did you know that:

- highest rate of volunteerism is in the 30-39 age range
- 46% of NSW volunteers are male
- 60% of volunteers are already in the work force, and
- volunteers come from many different backgrounds.

Work	xperience?	training?
stamping envelopes	no	no
newsletter mailout	no	no
photocopy work	no	yes
brochure send outs	no	yes
video production	yes	yes
audio production	no	yes
labelling	no	no
mailbook collating	no	no
computer entry	helpful	yes
bookkeeping	yes	yes
financial reporting	yes	yes
prepare sendouts	no	no
video librarian	no	yes
office filing	no	yes
database work	no	yes
newsletter articles	no	yes
committee work	no	yes
phone support work	no	yes

Community involvement (volunteerism) can be a very positive force for us all. Our best interests are in the future, because we're going to spend the rest of our lives there.

Give the office a call if you want to go onto the volunteer database.

I WANT TO HELP, BUT WHAT CAN I DO

One of the main Council services is the Telephone Information and Support Service - a service that has been in operation for over three years.

THE SERVICE was originally staffed by volunteers from the Council - in nearly all cases these were people who were directly affected by the hepatitis C virus and who lived anywhere in the state.

We now recruit from a wider volunteer base. Not only do we target the general community, but we also recruit specific people such as welfare and social work students, and volunteers from the Volunteer Association of NSW. Because such telephone services operate best out of a central base, our recruitment is now limited to the Sydney metropolitan area.

Of course, we always try to recruit from within our Council membership and here we rely on the information contained in our membership forms.

THE PEOPLE who staff the phone service come from a wide variety of backgrounds. Some people do phone work in order to put something back into the Council after having been members for some time. Others simply want to gain work experience in a welfare-related field (the work involves valuable skills, often including computer work). Most people simply enjoy being part of the service and meeting other people, some who are affected by HCV, others who come from different walks of life.

THE WORK involves a process that includes initial interviews to discuss your expectations and experience.

This is followed by training in communication, basic counselling and telephone skills, and an administrative overview.

Volunteers are then inducted into the service, working together with trained staff until they are ready to take on separate shifts. Ongoing supervision is provided, enabling volunteers to discuss calls taken and off-load if necessary.

We also have staff meetings (usually over lunch) where volunteers can get to meet each other in a more relaxed setting.

We extend an invitation to all Council members to become involved in our telephone service. This work, like other types of volunteer work at the office, can be tailored to suit you. Yes, the work offers challenges but the rewards can be great.

As Pamela, one of our current volunteers said recently, *"It's great. I've learnt a lot - from the training and from talking to so many differnet people."*

The next telephone service training is being held in March 1996.

If you are interested in the telephone service, or any type of Council work, please don't hesitate to **contact Paul on 02 332 1853.**

RPAH offers new hepatitis C tests

The Department of Gastroenterology at Royal Prince Alfred Hospital is now providing expanded testing for hepatitis C. The tests available include:

- HCV PCR tests - for detecting the presence of the hepatitis C virus RNA (a part of the virus itself) in someone's serum (or blood)
- Quantitative HCV PCR tests - for determining the level of virus (or titre) in someone's serum, and
- HCV Genotyping tests - for determining the particular hepatitis C virus subtype in someone's blood.

The detection of of HCV RNA is useful in people who have indeterminate (or unclear) HCV antibody tests. HCV PCR is not warranted for people who are HCV antibody positive and have persistently abnormal liver function tests (LFTs), as studies have show that over 90% of these people do have the virus in their blood (McGuinness, et al., 1993). The test is useful, however, for people who have HCV antibodies, but whose LFTs are normal, or are elevated for some other reason.

The clinical importance of quantification and genotyping is still being determined by clinical trials. HCV quantification, however, is currently recommended for pregnant HCV antibody + women in their third trimester.

Determining the level of virus in the serum and the HCV genotype may also be useful when deciding about Interferon treatment.

The tests will be provided free of charge to patients of RPAH. The services will also be available for private pathology clients at a cost of $50 for PCR, $75 for HCV genotyping, and $100 for quantitative PCR.

A short report from Jenean Spencer, RPAH Camperdown.

Reference - McGuinness, Peter et al., (1993) "Detection of Serum Hepatitis C Virus RNA in HCV Antibody-sero-positive Volunteer Blood Donors" Hepatology, 18:485-490

Spread of bloodborne viruses among Aust prison entrants

An abridged version of the Crofts et al., research paper published in the British Medical Journal - Feb 1995

A large proportion of prison entrants are sentenced because of their need to generate income to buy illegal drugs. Among Australian prison entrants, 37% to 66% have a history of injecting drug use.

In Australia, reported prevalence of HIV among injecting drug users is low and little HIV has been discovered in prison entrants. The prevalence of hepatitis C and hepatitis B is high, however, both being associated with injecting drug use, and hepatitis C also being associated with tattooing.

Several risk behaviours for transmission of hepatitis C, hepatitis B and HIV occur in prison, including the injection of illicit drugs and tattooing with inadequately disinfected equipment as well as unprotected sexual intercourse *[a greater issue for HIV & hepatitis B - Ed].*

OBJECTIVES

We tested for HCV, HBV & HIV among entrants to the central Victorian prisons (through which most people enter the Victorian prison system) to study the prevalence of these viruses, and the magnitude of the risk behaviours that spread them.

DESIGN OF THE STUDY

Over a 12 month period, we voluntarily and confidentially tested all prison entrants for markers of exposure to bloodborne viruses (blood test results) and collected information on each prisoner and his/her transmission risk factors.

STUDY SUBJECTS

We studied 3,429 male and 198 female prison entrants. This represented over 99% of all prison entrants over the 12 month period.

RESULTS

The main results were as follows:

- 46% gave a history of use of injected drugs
- 39% were hepatitis C antibody positive
- 33% were hepatitis B core antigen positive (past exposure)
- 2.5% were positive for hepatitis B surface antigen (current infection)
- 0.47% were positive for HIV
- Of prisoners aged less than 30 years old who inject drugs, the rate of new infections were 18.3 per 1000 prisoners for hepatitis C, and 12.6 per 1000 prisoners for hepatitis B.

CONLUSIONS

Hepatitis C & B are spreading rapidly through some populations of injecting drug users in Victoria - particularly among men aged less than 30 years in whose case the rates are extreme. This spread is occurring in a context of harm reduction measures for prevention of viral spread outside prisons, but few programs within prison or on transition from prisons.

KEY MESSAGES

- Australia has implemented widespread harm reduction programs outside prison but few inside or on transition from prison.
- These programs are seen to be effective in controlling the spread of HIV among injecting drug users, among whom the prevalence of HIV remains low.
- There is, however, continued spread at high rates of hepatitis C and B among young injecting drug users entering prisons in Australia.
- The highest rates (41% a year for hepatitis C and 21% a year for hepatitis B) are occurring among young male injecting drug users.
- There is an urgent need to refocus harm reduction programs to cope with the challenge of hepatitis C and to ensure prisoners are at no greater risk inside or on transition from prisons than they are in the general community.

HCV-friendly healthcare workers

A recent South Australian survey of several hundred General Practitioners showed that although most had a basic awareness of hepatitis C and wished to play a more active role in patient management, some were unsure about significant aspects such as hepatitis C prognosis, or criteria, availability and guidelines for Interferon treatment.

Many people living with hepatitis C contact the Hepatitis C Council of NSW asking if we know of 'good' doctors in their area. This is a perfectly reasonable approach to take as the general public are increasingly seen as customers of healthcare services within our healthcare system.

It would be arrogant for us to presume one doctor is 'good' while others are 'poor' and we have accordingly begun a project aimed at simply identifying healthcare workers who are 'interested' in HCV. To this end we are sending out our hepatitis C brochures to all doctors and specialists in NSW. A cover letter is sent with the brochure, attempting to recruit healthcare workers into this project.

International Prison Watch .. continued

(Continued from page 16)

has taken away remissions. This happened despite the assurances of politicians that the legislation would not result in increased imprisonment, but rather would be taken into account by reduced sentences.

The removal of remissions has resulted in:

- a greater sense of prisoner despondency and low morale
- dislocation and institutionalisation, and
- increased drug use and dependency.

Further, there has been an expansion of the culture of prison informing, now the only means prisoners have to reduce their sentences. This has increased numbers of prisoners on protection and created further divisions within the gaols.

There clearly need to be incentives for positive behaviour and participation in education and skills programs.

DEATHS IN CUSTODY

There have been been 27 Aboriginal deaths in NSW gaols since June 1989, seven of which occurred in 1995. This is the highest 'deaths in custody' figure since 1980. Four of these deaths were men under the age of 25. The Aboriginal Deaths in Custody Royal Commission's recommendations have yet to be properly implemented.

The deaths of both Aboriginal and non-Aboriginal prisoners are a reflection of many factors including:

- the unreasonable imposition of custodial sentences (in NSW, Aboriginal women make up 25% of the prison population serving sentences of 3-6 months)
- the loss of community support
- the lack of incentives, and
- the sense of hopelessness felt by prisoners.

"prescribed medication is used as a tool for prison management"

DRUG USE IN PRISONS

Drug use in prisons is rife, reflecting the extent of drug related charges, the inadequacy of current drug laws and the prisoner's need for retreat from the harsh realities of gaol life. Figures of prisoner involvement with drugs are estimated to be as high as 80%.

Drug use by female prisoners is believed to be at a higher rate than that of male prisoners, but the pattern is different - many women use prescription drugs such as sedatives, sleeping pills and methadone.

Anecdotal evidence points to drug use, both legal and illegal, as a condoned means to keep the prisoners under control. Prescribed medication is used as a tool for prison management without concern for the long-term health consequences or the prisoner's welfare when they return to the community. There is a focus on the ease with which prisoners can be sedated and controlled, and the cost effectiveness of this kind of management.

There are inadequate drug and alcohol counselling services and insufficient drug detoxification facilities or, as is the case with Mulawa Correctional Centre for Women, there is no detox unit at all.

(Continued on page 24)

AHMAC Prevention 'Approach'

The Australian Health Ministers Advisory Council (AHMAC) has recently endorsed a strategy aimed primarily at reducing transmission of the hepatitis C virus.

The Nationally Coordinated Hepatitis C Education & Prevention Approach was prepared by a 20 member 'Reference Group' that included Susan Carruthers of the Hepatitis C Council of WA, and Stuart Loveday from our NSW Council.

The "Approach" aims to reduce transmission of HCV by 50% by the year 2000 and acknowledges that the transmission of HCV occurs overwhelmingly through blood to blood contact. Accordingly, the Approach primarily targets people who inject drugs, people who provide tattoos or skin piercing, health-care workers and prison staff.

The Reference Group acknowledges that the information, care and support needs of people affected by hepatitis C are best met through a separate strategy. The Commonwealth Health Department recently endorsed a proposal put by the various state hepatitis C organisations - ***a national needs analysis project.*** This project will draw from, and expand upon, surveys that have been done or are underway (see page 9). The results will provide us with a clear direction for the further development of information, care and support services.

Working within this field, it often seems that the answers are staring you in the face, but without detailed, planned, controlled studies, we could easily end up with second-rate services and wasted resources.

It is vital that many people who have HCV are involved in the eventual study. The various Hepatitis C Councils will strive to make this possible and will keep you informed about the project.

International Prison Watch .. continued

(Continued from page 23)

BLOODBORNE COMMUNICABLE DISEASE (BBCD)

Prevalence of hepatitis C in NSW prisons is over 35% - 160 times its occurrence in the general community. Prevalence of HIV in our prisons is up to 40 times that of the general community.

A Community Policy, *Prisons and Bloodborne Communicable Diseases*, calls for more education and effective programs to reduce the spread of BBCDs and to improve care and treatment for positive prisoners.

Recommendations include:

- prisoners must have confidential access to new injecting equipment on a strict exchange basis, as is available in the general community
- prisoners must have free, unrestricted and confidential access to dams, condoms, latex gloves and water based lubricant
- prisoners must have the right to associate or not associate with any prisoner in their cell or in general areas, and
- prisoners should be given the right to have sex with visitors.

Programs and practices must be developed to address women's particular needs including:

- issuing prisoners with sanitary products
- provision of counselling for women who self mutilate, and
- identifying the needs of the families of positive prisoners.

In both male and female gaols, a greater focus should also be placed on hepatitis C and hepatitis B as well as HIV.

INMATE DEVELOPMENT COMMITTEES (IDCs)

There is a lack of prisoner involvement in prison management. The Department's operational agreement providing for elected Inmate Development Committees must be properly implemented and supported.

IDCs allow prisoners to have some responsibility over their own lives by:

- identifying the relevant issues and deficiencies in jails
- developing and promoting positive dialogue and understanding between prisoners and staff
- prioritising education needs, and
- the creation of post-release programs.

COMMUNITY ACCESS TO PRISONS

Greater access to gaols is needed. A visitors' survey indicated shortcomings in the provision of facilities and services for visitors.

A scheme to give wider access to community groups and individuals, at the invitation of prisoners or Inmate Development Committees must be developed. For example, Justice Action has commenced a weekly roster of volunteers to visit Mulawa Correctional Centre and assist the women with their cases and the problems they face while in custody.

RIGHTS FOR PRISONERS

There needs to be a statement of prisoners rights derived from the International Covenants and community standards, and a mechanism for it to be implemented. Prisoners generally do not have the right to vote although they are controlled, fundamentally, by laws created by politicians. This denial epitomises and exacerbates their isolation from the community and raises legitimate resentment.

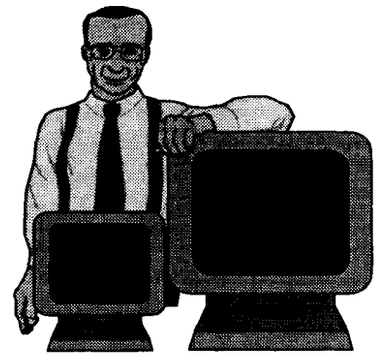
justice
ACTION - 02 281 5100

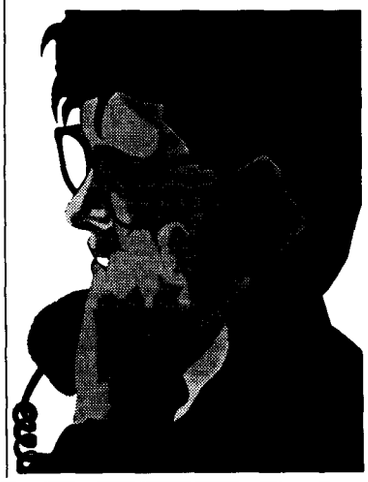
VIDEO PROJECT

Information and support can be delivered effectively by video. We are seeking volunteers to produce short videos.

Have you any training in video production? Do you want to pick up new skills?

You would work in a small team and need to commit to 2 days a month. We will supply training.





TELEPHONE INFORMATION & SUPPORT WORK

Our next training day for phone workers is in March 1996.

The volunteer work is very rewarding and the minimum commitment is 4 hrs a week.

We are seeking recruits, willing to work in a team operating out of our office in Surry Hills / Darlinghurst (we are on the 302-3 and 339 bus routes). Full training and supervision is offered.

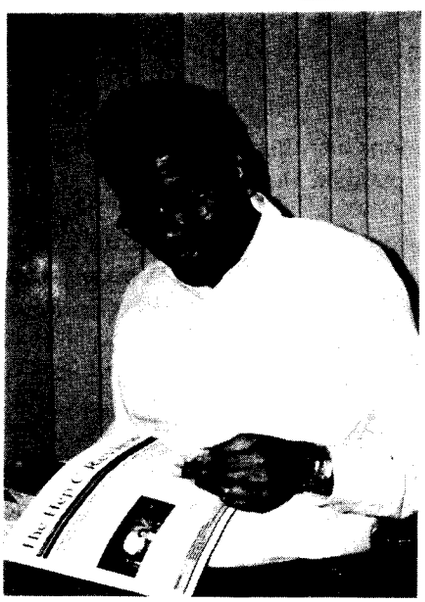
Close encounters of the photographic kind

Tied in with our Annual Report (following page) are some 1994/95 snap shots.

Pictured anti-clockwise from above right is *Paul Harvey* (then President) meeting with *Clover Moore MP*, Independent Member for Bligh.

Smiles all round at the Newcastle office opening, pictured are *Professor Bob Batey* and *Cheryl Burman* (current President) - *Leone Robertshaw* (Hunter Branch Convener) putting last minute touches to the opening ribbon, hey watch out for the old guy on the horse! - *Sandy Beringer* (Infection Control Consultant, John Hunter Hospital) - and *Ranjit Patterjee* (Hunter Branch Committee member) enjoying the view.

Left to right, below, *Sharon McKenzie* (Prime TV) and *Marilyn Bliss* (Hunter Region HIV Sexual Health Coordinator) celebrate the office opening in style; *Rose Anderson* (Hunter Branch Treasurer) takes a congratulatory call.



Hunter support groups

We operate regular support groups in Newcastle and Muswellbrook offering people who are affected by hepatitis C the chance to meet others and hear guest speakers talk about hepatitis C matters.

If you are interested in talking to someone about the support groups, contact Leone or Rose on 049 252 511 (Newcastle) or Robyn on 065 432 677 (Muswellbrook).

The Hunter Branch may also be able to assist if you seek specific hepatitis C information or referral to professionals for one-to-one counselling.

Hepatitis C Council of NSW - Annual Report 1994/95

Our Council grew out of a patient support group at Westmead Hospital in Sydney, set up in November 1991 to provide support for people affected by hepatitis C and to represent their interests within the broader community.

A toll-free 1800 telephone support line involving a network of city and country based volunteer workers was established. Soon after, the group increasingly began to address public and peer education needs.

Work started to include Federal issues as well, such as access to treatment and social security pensions. Liaison with peer health and welfare based agencies also increased rapidly. Following consultations with other state groups, the national *Australian Hepatitis C Support Group* was incorporated in February 1993, achieving charitable status soon afterwards.

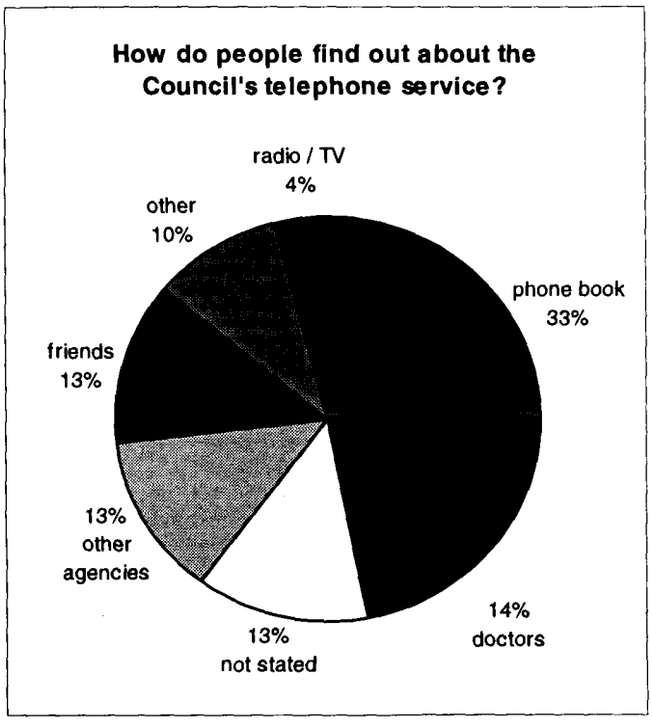
With Federal funding submissions rejected, the group was unable to function on a national level and in July 1994, the association reformed as *The Hepatitis C Council of NSW*, moving to its first offices in Surry Hills, Sydney.

1994 also marked the *NSW Health Department's* formal acknowledgment of the Hepatitis C Council's role by providing ongoing funding for the provision of counselling and support services. This marked the beginning of a shared commitment to address hepatitis C needs within the NSW community.

Phone information and support

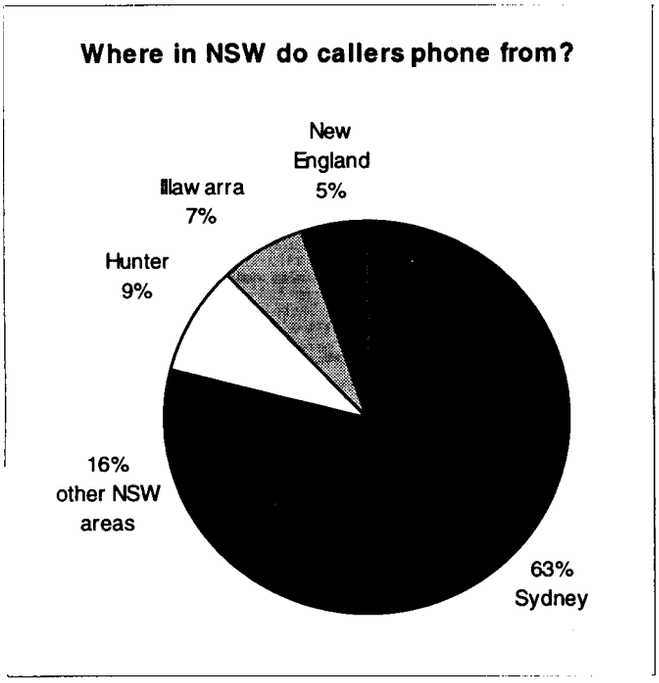
Callers to the freecall 1800 line are referred to a range of metropolitan and non-metropolitan telephone information and support officers. The line was limited to NSW callers at the time of the changeover from a national to a state-based Council, although we continued to provide limited services on our pay lines to callers from other states.

The introduction of statistics forms in January 1995 meant we were able to record, for the first time, the quantity, content and quality of the calls our trained volunteers and staff dealt with. Of the 2,112 calls received in the 6 months to June 1995, we were able to respond effectively to 726.



Of the 726 calls we were able to respond to:

- 53% dealt with both information and support matters
- 25% of callers were in the 31-35 age group, and 87% said they found our service useful or very useful
- treatment was the most common subject discussed, followed by questions on transmission and the possible outcome of hepatitis C infection
- of callers, 33% were people with hepatitis C, and 24% were partners, friends or family of people with hepatitis C. Interestingly, 66% of callers in the 6 month period were women. Six percent of callers identified as healthcare workers, and 16% said they were people who had injected drugs at some time
- a majority of calls were from the Sydney area, followed by the Hunter, Illawarra, New England and other NSW areas



- 43% of callers were offered referral to other agencies for specific additional services
- over 50% of the calls were between 6-20 minutes long, with 16% being over 20 minutes in duration

The need for this service to be expanded is overwhelming. We need to extend the hours it operates, and also to make the service a truly freecall line. Callers should not have to make a second or even third phone call, often at great expense to themselves.

Public speaking, education and training

Committee member, Rod Charls facilitating a recent skills development workshop.

Staff, committee members and guest speakers presented 23 information and education sessions in 1994/5. These included:

- a training course for telephone information and support volunteers in June
- three CEIDA (Centre for Education and Information on Drugs and Alcohol) healthcare worker information updates
- several public information meetings in Sydney, Newcastle and Muswellbrook
- awareness days in Orange and Sydney
- a presentation at the Australian Hepatitis C Symposium in Terrigal
- information presentations for the DSS, HIV organisations, Mulawa Women's Prison, Leichhardt Women's Community Health Centre, needle exchange projects, the Australian Traditional Medicine Society (ATMS) and for commercial employers

Staff and committee members attended seven conferences and seminars in the year. These ensured we were kept abreast of emerging hepatitis C developments.

HCC information materials & resources

The Hep C Review

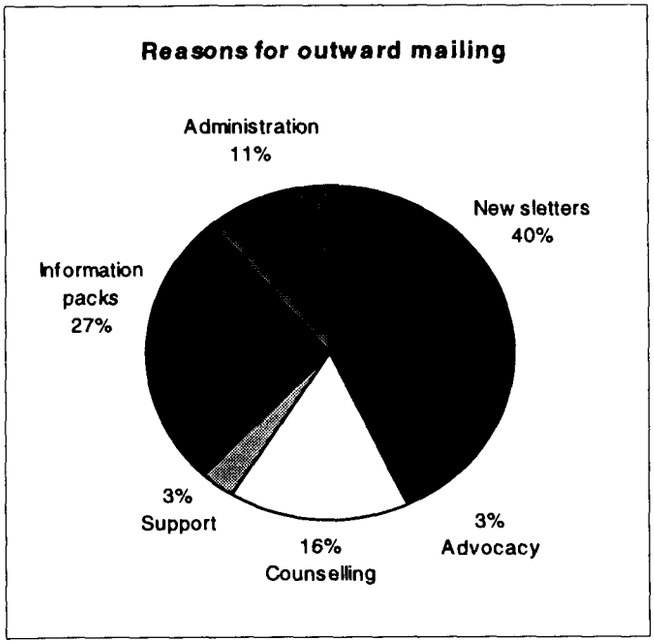
Our quarterly newsletter, *The Hep C Review*, with a print run of 3,500 continues to cover a broad range of subjects from interferon and natural therapies treatments to funding, and from regional news to infection control discussions. Possibly the most widely read regular hepatitis C journal in Australia, *The Hep C Review* remained a source of support, contact and information for our members and many healthcare and welfare professionals.

Information Sendouts

A total of 5,400 mailings went out in 1994/5. Almost 1,500 updated information packs were distributed across NSW.

Information Videos

1994/95 saw the welcome introduction of information videos. Three were produced, covering interferon and general information, natural therapy treatments, and women and hepatitis C. Our hepatitis C videos are available on loan, free of charge to members.



Resource Manuals

In August 1994 the Council produced three resource manuals for our information and support workers: Telephone Counselling Support Manual, Referral Resource Manual and Strategies for Effective Communication. These have been put to good use during the year.

Research Packs

Three research information packs were collated for healthcare workers, peer agencies and other interested people, providing copies of research papers and government planned responses to the hepatitis C epidemic.

Representing the interests of people affected by hepatitis C

During the year, we successfully lobbied for interferon to be listed under the Federal Pharmaceutical Benefits Scheme, allowing for free treatment, and made detailed submissions recommending development of the AHMAC National Action Plan and the NHMRC Guidelines for HCV Clinical Management.

Council members and staff were appointed as representatives on two major government advisory committees:

- the Australian Health Ministers Advisory Council (AHMAC) Education and Prevention Reference Group
- the NSW Hepatitis C Taskforce

We organised and hosted a highly successful NSW Parliamentary Briefing in November 1994. This ensured NSW politicians were updated on the urgent needs facing people with hepatitis C. At the briefing, clear messages of support were received from Dr Andrew Refshauge, who has since become Minister for Health and Deputy Premier.

Individual and general casework was carried out in employment discrimination, housing and medical service provision. We were influential in getting disability support pension eligibility criteria clarified.

We met regularly with NSW and Federal health department officers, keeping them informed of community needs, and lobbying for more resources for people affected by hepatitis C.

Stuart Loveday, Dr Andrew Refshauge, Margaret Gearin at a recent meeting to discuss health services for people with HCV.

We started work, continuing into the 1995/6 year, on the development of the community policy that would recommend major changes to practices in NSW prisons. Its main goals are to help prevent the further transmission of hepatitis C and provide adequate treatment, care and support for people in corrective services institutions.

A range of TV, radio and newspaper interviews and contributions by Council committee members, other volunteers and staff meant that hepatitis C has been kept in the public eye.

Working with peer agencies

With extensive networking, particularly in information provision and referral services, we have been able to use fully the support available from existing services. Regular communication and referrals took place with:

- *gastroenterologists, hepatologists, virologists, immunologists, the AGI, all NSW interferon prescrib-*

ing hospitals, general practitioners, women's health centres, blood banks, methadone clinics, drug and alcohol services, Public Health Units, Area and District Health Services and Aboriginal health workers

- *NSW Health Care Complaints Commission, Infected Healthcare Workers Advisory Committee, NSW Department of Corrective Services, NSW Prison AIDS Project (now the HIV & Health Promotions Unit), DSS, Homecare NSW, DOCS, and HACC*
- *NUAA, the Kirketon Road Centre, the Albion Street Centre, CEIDA, NCOSS, ADIS, our regional volunteers and support groups, other hepatitis C Councils across Australia, Haemophilia Foundation, the Gay and Lesbian Counselling Service, ACON, AIVL and AFAO*
- *crisis support services, children/relationship and family support services, politicians, unions, translation services, peak natural therapy professional organisations, community legal centres, the Anti Discrimination Board and the Human Rights and Equal Opportunities Commission*

Regional and metropolitan support

Regular monthly support groups started in Newcastle, where the Council's first branch, the Hunter Branch, staffed entirely by volunteers and supported by Hunter Public Health Unit was established in March 1995.

Members of our Council's Hunter Branch, gathered for a planning meeting, prior to moving into the Hunter offices - Shop 2, 317 Hunter Street Newcastle, ph 049 252 511.

Other support groups met in Bathurst, Central Coast, Coonabarabran, Lismore, Orange, Tamworth, Upper Hunter, Wagga Wagga and Wollongong.

The demand for support and information groups in all areas of NSW was a constant call throughout the year. However without dedicated and adequate resourcing, this call was unable to be met by our Council.

One-to-one counselling was provided from the Sydney office for part of the year.

Our human resources

Our dedicated **volunteers**, the backbone of the Council, worked long and hard. Our heartfelt thanks go to our 24 telephone information and support officers, 10 office volunteers and your Management Committee members who performed invaluable tasks throughout the year - often far too late into the night.

Personnel

- **President:** Cheryl Burman (Paul Harvey to May 1995, Warren Wright to August 1994)
- **V. President:** Bernard Fischer (Cheryl Burman to May 1995, Paul Harvey to August 1994)
- **Treasurer:** Anita Long
- **Secretary:** Richard Booker
- **Other Members:** Rod Charls, John McKenzie and Steve Hopper (also during 1994/5: Jeff Dwyer, Linda Forbes, John Saunders, Ashley Scarlett)

The Management Committee held regular meetings throughout the year, including a strategy planning day in September 1994, and continued to take overall responsibility for the operations of the Council.

The staff of the Council in the year were:

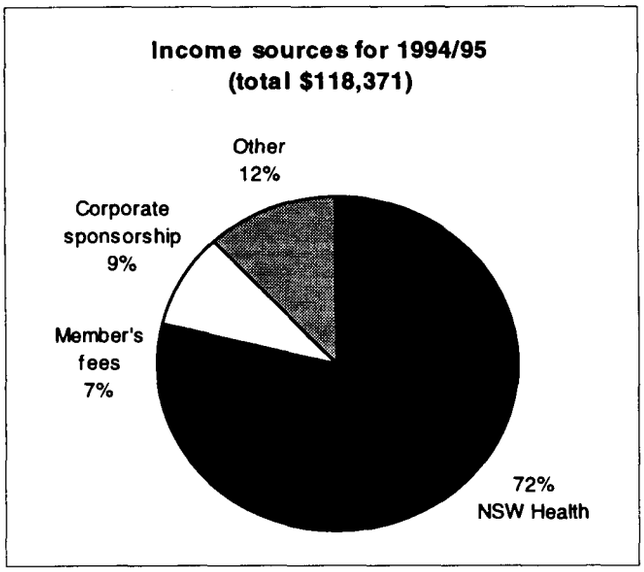
- **Admin/Finance Assistant** - Prue Astill, Judy Sau-chung Cheung (11/95 to 12/95)
- **Senior Project Officer** - Paul Harvey
- **Coordinator** - Jennifer Horton (to 8/94)
- **Executive Officer** - Stuart Loveday

Our **Medical Advisory Panel**, established during the year to provide information, guidance and expert advice on clinical and related matters comprised Professors Geoff Farrell, Bob Batey, Yvonne Cossart and Geoff McCaughan, and Drs Ingrid van Beek and Alex Wodak. Our sincere thanks go to them.

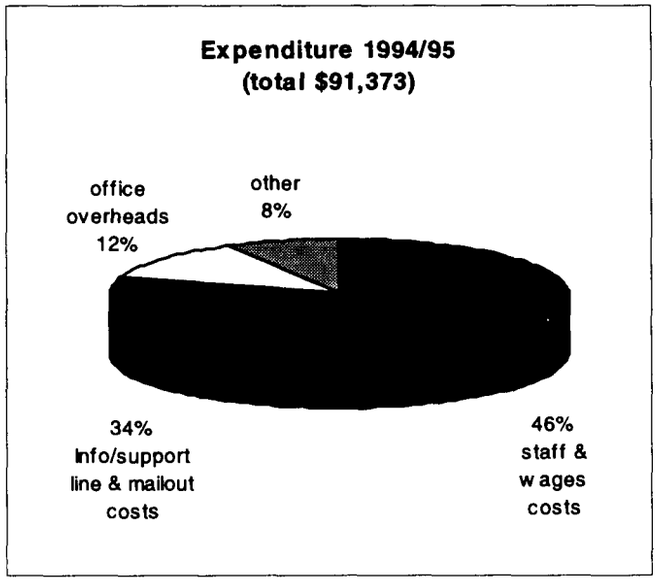
Finances

HCC-NSW income for the year was $118,371. We gratefully acknowledge the support of NSW Health who funded us with a core operations annual grant of $86,000. Membership fees accounted for $7,800. Corporate sponsorship and donations made up $10,673 and

grants in advance, interest and product income amounted to $13,898. Our sincere thanks go to members, sponsors and donors for your ongoing support.



Our major revenue expenditure was on staff and wages followed by information and support line costs, office overheads and other costs. Other costs included computer software, depreciation and minor expenditure.



Our capital purchase of a high volume photocopier, computer and video equipment, made possible through NSW Health's initial seeding grant, enables us to produce high quality information and resource materials.

Formal budgeting and cash flow forecasting and a revised code of financial procedures were introduced in the year. Credit card facilities were also introduced to make it easier for members to pay subscriptions.

Bryan Rush and Co were reappointed as Council auditors at the 1993/4 AGM.

With a small operating surplus in the year, our priority remains securing medium to long term ongoing funding: essential to ensure maintaining existing services, and vital in order to expand our primary information and support provision so that we can meet more effectively the huge demand for our services.

The future

General areas of work in the 1995/96 year will include

- continuation and expansion of existing services
- expanding the telephone information and support service to increase the number of calls taken
- acquiring secure medium or long-term office accommodation
- continued lobbying for coordinated, well resourced action to be taken both on a state and national level: in particular, to call for effective implementation of the National Action Plan
- increased liaison within GPs and pharmacies
- review of information booklet
- production and distribution of our new brochure *Hepatitis C - a brief introduction*
- boosting management committee membership and implementing postal voting, upon planned adoption of our proposed new constitution
- establishment of a Natural Therapies Advisory Panel
- expansion of our strategic plan by development of an organisational business plan.

Stuart Loveday
Executive Officer

(Full financial statements are available from your Council office)

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. All you will need to pay is 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?
Brochures	An A4, two fold brochure giving an overview on hepatitis C	$5 per 100
Hepatitis C Info 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.	no cost
Newsletter back issue pack	Topics include Social Security, Disability Support Pension, Interferon treatment, natural therapies.	no cost
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 homoeopathy, 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	2 Quantum episodes: - hepatitis C - the Liver	$3.00 return postage
Research Pack No 1	Hepatitis C research papers - overview, prevention, diagnosis, serology, epidemiology (1993-1995).	none
Research Pack No 2	AGI booklet (1994), Fairfield Hospital healthcare provider booklet (1994), National Hepatitis C Action Plan (1994).	none
Research Pack No 3	NHMRC Hepatitis C Report (1994)	none
Research Pack No 4	WA Dept Health HCV booklet (1995), hepatitis C research papers	none
Research Pack No 5	AHMAC - The Nationally Coordinated Hepatitis C Education & Prevention Approach (1995), NSW Health Taskforce Report (1995)	none

Audio Cassette copies of some of the above publications are available if your eye sight is a problem and you can't understand them in the written form - it would be greatly appreciated if volunteers could help with the production of these tapes.

Regional Support Groups

For information on Regional Support Groups, please phone the following contacts (during business hours):

Newcastle: Leone or Rose on 049 252 511
Tamworth: Margaret on 067 683 365
Dubbo: Nick on 068 828 765
Coonabarrabran: Gary on 068 422 507
Muswellbrook: Robyn on 065 432 677
Orange: Phil on 063 617 455
Bowral: Andrew on 014 419 974
Bathurst: Christine on 063 315 584

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 your cheque, money order or credit card details to:

Hepatitis C Council of NSW
PO Box 432 Darlinghurst NSW 2010

Cheques etc should be made out to Hepatitis C Council of NSW

1. Please complete either a, b or c.

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.

$ yes / no for publication?

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	Membership no.	Info pack