

GOOD LIVER

NEWSLETTER OF THE HEPATITIS C COUNCIL OF VICTORIA



NOW, LATER OR NEVER? CHALLENGES OF HEPATITIS C TREATMENT

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While there is good understanding of clinical factors that may enhance successful treatment, little research has examined routes into hepatitis C treatment and decisions about treatment uptake from the perspective of the potential patients, those currently and previously on treatment, and medical practitioners involved in this process.

There are many factors which influence the decision to commence and to adhere to treatment. From the perspective of the person with hepatitis C, treatment involves a heavy time and possibly heavy financial commitment, involving weekly visits to a hospital or clinic for between six and twelve months. The fact that symptoms of hepatitis C are sometimes not as significant for an individual as the side effects of treatment makes the decision to begin treatment particularly difficult for

some. Uncertainty associated with the success of outcome may also limit willingness to begin and maintain treatment. People may worry about the impact of compliance requirements on family and work commitments, and whether they will perceive any discrimination from treatment staff. Psychological side effects of treatment can be a serious concern, particularly the potential impact of treatment-induced depression. Finally, there are potentially serious life changes required e.g. abstinence from alcohol, from drugs, pregnancy (as one treatment drug is teratogenic*), etc. For injecting drug users, the required changes in lifestyle may be particularly difficult to achieve and sustain.

There are a number of decisions also to be made on the part of the medical practitioner managing a patient with hepatitis C. When should a general practitioner (GP) test someone for hepatitis C? When should the patient be referred to a Specialist Physician? Does the patient have a pre-existing psychiatric condition that might be exacerbated by the treatment? Are there risks of re-infection? Will the patient have appropriate social support from their family or wider social network?

THE STUDY:

This is a unique study because it examines treatment issues from three different perspectives - that of the person with hepatitis C, the GP and the Specialist Physician. In addition, the views of people with hepatitis C who have considered but rejected treatment, as well as those who have previously been on treatment, and those who are currently on treatment, were sought. This has provided a wealth of data that can be used to make recommendations for improving both hepatitis C treatment uptake and adherence to treatment.

Questionnaires for people with hepatitis C (n=224), GPs (n=90) and Specialist Physicians (n=113) were answered during August 2003- April 2004. Focus groups were also conducted with people with hepatitis C and GPs, and these were completed by May 2004.

This article will focus mainly on the responses from the 224 people with hepatitis C who completed the survey from throughout Victoria. They came from various places, including clinical settings, drug and alcohol services, community networks and through a mail out to people who had participated in previous hepatitis C studies and were willing to be involved in future research.

*leads to foetal abnormalities



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Reader Response

Your comments or experiences in regard to any articles in the Good Liver are welcome. Call, write or email: heathers@vicnet.net.au

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news:

HIV/AIDS AND HEPATITIS C INFORMATION WEBSITE

Australian multilingual website with HIV/AIDS and hepatitis C information for people from culturally and linguistically diverse background and for health care workers in Amharic, Arabic, Bosnian, Burmese, Chinese, Croatian, English, Indonesian, Italian, Khmer, Portuguese, Serbian, Somali, Spanish, Tagalog, Thai, Turkish, and Vietnamese.

Funded by the Australian Government Department of Health and Ageing, the new website has more than 400 pages of HIV/AIDS and hepatitis C information in 18 community languages.

LIVER DONORS UP

THE donation of livers had risen dramatically since the formation of the David Hookes foundation in February this year.

Royal Prince Alfred Hospital director of transplantation services Professor Richard Alien said the publicity surrounding the death of cricketer David Hookes in January had helped people agree to liver donation.

Prof Alien said the rise was also due to the ability of surgeons to split the liver into two parts, the smaller part for a child and the larger for an adult.

Herald Sun, Melbourne Oct 2004

WEB FORUMS

There are two excellent web forums available at the moment.

1. The Australian Hepatitis Council is now running its web forum for professionals in the hepatitis C sector. Check it out at: www.hepatitisaustralia.com/forum/publicaccess/

2. For people generally affected by hep C, the very interesting and active NSW community forum can be found at: <http://hepatitisc.communityzero.com/hepcnsw/>

DRUGS ADDED TO PBS

New drugs for hepatitis B and C, HIV, lung and breast cancer will be added to the Pharmaceutical Benefits Scheme from December costing \$28million this financial year.

Financial Review, 8 Oct 2004.

HEROIN KITS ON DEMAND FOR SCOTS PRISONERS

SCOTTISH jails will give heroin injection kits to prisoners under a hugely controversial plan to combat the spread of blood borne viruses.

Hundreds of inmates will be handed clean syringes and swabs on a 'no questions asked' basis as a result of the scheme, which was condemned by some as the ultimate surrender in the war on drugs.

Prison health managers openly admit the drugs problem is so rife they have no alternative but to help inmates take highly addictive Class A drugs safely, even if that means turning a blind eye to rampant law-breaking within jail.

It is estimated that 80% of convicted criminals entering prison are on drugs, 40% of whom use heroin. One in 10 Scottish prisoners receives methadone.

Dr Andrew Fraser, head of healthcare for the Scottish Prison Service (SPS), fears an epidemic of Hepatitis C, and other blood borne diseases, will sweep through jails and beyond unless urgent safety measures are taken.

<http://scotlandonsunday.scotsman.com/>

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"HAPPY SUPPORT GROUP"

The December Support Group will be a special Christmas meeting.

Sunday 12 December
2 to 4pm

All those that have attended a support group meeting during the year are especially invited to attend.

A naturopath has also been invited who will be able to answer all your questions on managing the symptoms of hepatitis C using natural therapies.

For more information contact Pier on 9380 4644 or email: pier@hepcvic.org.au

MEMBERS ADVISORY GROUP

NEXT MEETING: 13 MARCH 2005

- Would you like to know more about the Council?
- Do you have ideas about how the Council could work better for you?
- Would you like to have your say about how the Council works?

If so, then the Members Advisory Group (MAG) is the forum for you. MAG is the Council's forum where members can have a voice. For more details contact Pier on 9380 4644 or email: pier@hepcvic.org.au

HEPCHAT BREAKS FOR THE HOLIDAYS

From late December to the end of January, HepChat will take a summer break.

The first program will be back on air from Thurs 3rd Feb 2005 from 10.30 to 11am.



Welcome to the Summer 2004 issue of Good Liver. In this edition I would like to focus on the Committee of Management (CoM) of the Hepatitis C Council of Victoria. We had our Annual General Meeting in October, and the new committee for this financial year is now in place. Having a Committee of Management with a diverse range of skills and expertise, and adequate representation from the hepatitis C affected community is vital to the functioning of the Council.

We have sadly farewelled 5 committee members:

- **Mark Young:** (Open Family). Mark has been a CoM member since 1998, and played an important part in the Councils development over the years. Mark has been nominated for lifetime membership of the Council as an acknowledgement of his outstanding long-term contribution.

- **Danielle Croall:** (Hepatology nurse, St Vincent hospital). Danielle played an important part in keeping the Council in touch with what is happening in Liver Clinics.

- **Andrea Khan** (resigned Feb 04). Andrea was employed at the Victorian Aboriginal Health Service during her time on the CoM. Andrea has now taken up a management position at the Aboriginal Housing Board. Andrea provided fantastic representation from the Victorian Aboriginal community.

- **Jill Meade** (resigned July 04). Jill has had long-term involvement with the Council as she was the Manager for a number of years. Now working in the Northern Territory, Jill's extensive knowledge was a great asset.

- **Danielle Elston.** Danielle has extensive experience in government liaison and media relations. Her previous position with the Australian Hepatitis Council brought an important national perspective to the committee.

We are extremely grateful for the contribution of each of these people and wish them well in their new endeavours.

Three new CoM members have been welcomed for 2004/2005. They are:

- **Dr Eugenie Tuck:** Medical Director, St Vincent's Correctional Health Service

- **Geoffrey Hay:** community representative

- **Bev Greet:** Victorian Aboriginal Community Controlled Health Organisation (Bev is the secretary of the CoM this year)

Each of these people bring vital knowledge and expertise related to a different aspect of the hepatitis C epidemic. We look forward to working with them this year.

Other members of the committee for 2004/2005 are:

- **Jacqui Richmond:** St Vincent's Hospital. (Chair)

- **Mark Stoové:** Turning Point. (Vice Chair)

- **Cathy Mead:** Victorian Public Health Research and Education Council. (Treasurer)

- **Sandy Breit:** Haemophilia Foundation

- **Dr Rodger Brough:** Australian Rural Centre for Addictive Behaviours

- **Mark Farmer:** Community representative.

- **Michelle Thompson:** Foot patrol

A co-opted position for a person from an organisation representing injecting drug use issues will be filled shortly.

I believe that we are incredibly fortunate to have such a talented and diverse committee who give their time on a voluntary basis to ensure that the Hepatitis C Council of Victoria is governed in a way that ensures that it is strategically positioned, both now and in the future.

I wish all of our members a happy and safe festive season, and I look forward to working with you in 2005.

Helen McNeill
Executive Officer

CHALLENGES OF TREATMENT CONTINUED FROM FRONT PAGE

People with hepatitis C in this study:

- Average age 43 years
- 81% born in Australia
- 54% employed either full or part-time
- 26% unable to work due to illness
- 36% regional/rural residents
- Average time since diagnosis of hepatitis C was 7 years - ranging from 1997-2003
- Average time since contracting hepatitis C was 18 years - ranging from 1950-2003
- 47% rated their health as poor to fair
- 63% were currently experiencing symptoms

Given that so many participants reported hepatitis C related symptoms and poor health generally, it was surprising that only half were currently seeing a GP for their hepatitis C. People who were currently injecting were even less likely to see a GP for their hepatitis C. While most people who were seeing a GP for their hepatitis C were confident of their doctor's level of knowledge about hepatitis C, people's level of satisfaction with their GP in relation to their hepatitis C was below 50%. GPs play a very important role in managing and referring on people with hepatitis C. For most people it was a GP who ordered their hepatitis C test. Nearly half (46%) of participants rated their normal GP as being important in managing their hepatitis C. Sixty four percent rated doctors at a liver clinic, and 53% rated Specialist Physicians as being important in managing their hepatitis C.

Most participants (81%) had received a referral to a specialist clinic (n= 218). Less common referrals for further support were referrals to health care workers (33%), information about hepatitis C community services (58%) and information about alternative therapies for hepatitis C (32%).

Sixty nine percent of people with hepatitis C had seen a Specialist Physician about their hepatitis C and most (60%) were currently seeing a gastroenterologist or infectious diseases physician on a regular basis. About half (49%) of the participants saw a gastroenterologist or infectious diseases physician within 6 months of

receiving their positive hepatitis C diagnosis. Participants diagnosed in the past 5 years (69%) were significantly more likely than those diagnosed more than five years ago (35%) to see a gastroenterologist or infectious diseases physician within 6 months of their diagnosis. Most respondents (66%) were either satisfied or very satisfied with their current level of care from their Specialist Physician.

Of the 45 people currently on treatment 77% were on pegylated interferon plus ribavirin, compared with 71% (n=65) of those previously on treatment who were on standard interferon plus ribavirin.

DECISIONS ABOUT TAKING UP TREATMENT

Most important reasons for taking up treatment

Participants were asked to rate a range of personal/social and treatment related issues to indicate the importance of particular decisions about treatment uptake. Participants' responses were recorded on a 5 point scale (ranging from 1 = 'not important at all' to 5 = 'very important'. A not applicable category was also included).

Factors that were important in deciding to start treatment were similar for those who had undergone treatment in the past (n=65) and for those currently on treatment (n=45).

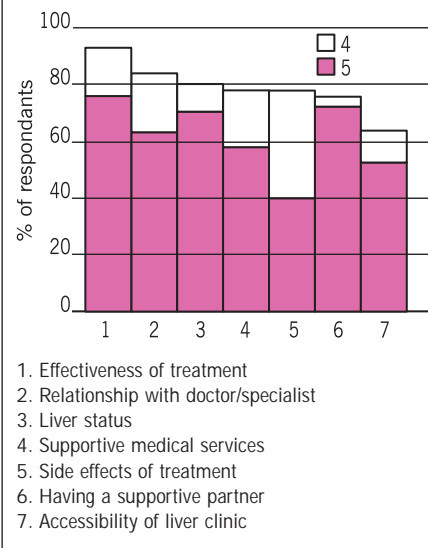
Two major themes were apparent in the decision to commence treatment:

1. The patient's perception of the likelihood of success for them personally
2. Their relationship with the doctor and the clinic managing the treatment (See Figure 1)

While treatment related issues were clearly the most important issue when deciding to take up treatment, having a supportive partner was consistently the most important social/personal issue taken into account for those currently, previously and for those still considering treatment. Issues considered not to be important when deciding to take up treatment included the need to use contraception, difficulties managing drug administration, fear of liver

Figure 1: Most important issues when deciding to take up treatment by people currently on treatment (n=45)

(5point scale: 1 is 'not important at all', 5 is 'very important')



biopsy, fear of discrimination and costs associated with treatment.

Reasons why people decided against treatment

For almost all of the people who decided against treatment, *side effects of treatment* were the most important issue. Other issues rated as important by at least half of those who decided against treatment were:

- Treatment success rates still not good enough
- The impact of treatment on work, family and friends
- Their liver status was still good.

Accessibility of a liver clinic was an important factor in deciding against treatment for rural residents. Almost 66% stated this was important in making the decision not to proceed with treatment, in comparison to 34% of metropolitan residents.

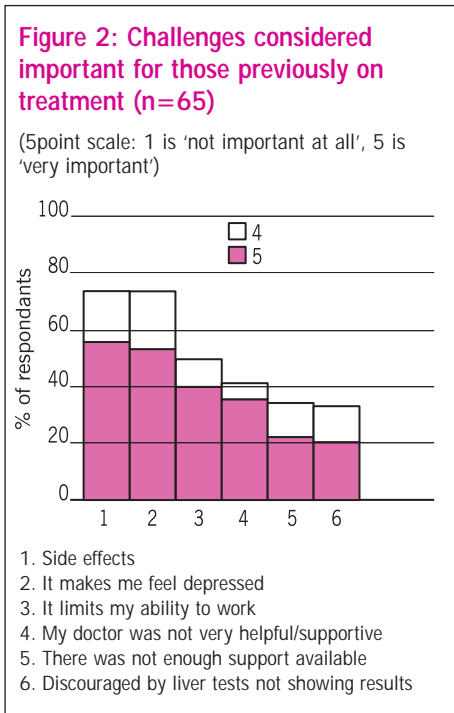
CHALLENGES ASSOCIATED WITH TREATMENT

The main challenges associated with staying on treatment

For those people currently on treatment, side effects of treatment and the association of treatment with depression

were the two highest rating challenges. Over 70% of participants who had previously been on treatment also rated these issues as important.

Overall the challenges associated with staying on treatment which were considered important rated much higher for those previously on treatment than for those currently on treatment, for example: 72% of participants previously on treatment and only 55% of participants currently on treatment considered side effects important;



72% of participants previously on treatment and only 43% of participants currently on treatment considered treatment's effect on depression as important. A similar relationship can be found for other challenges considered important.

Forty one percent of participants previously on treatment stated that an important challenge associated with staying on treatment was due to their doctor not being very helpful and supportive. This factor was rated much lower by participants currently on treatment with only 15% stating this was important and more importantly 70% of those currently on treatment rated this issue as not important.

(See Figure 3)

Experiences associated with Liver Clinics, such as accessibility, delays at clinics, consulting times not suiting, never enough time with the doctor and seeing different

doctors at the clinic were all issues considered not important challenges to staying on treatment by both participants previously on treatment (see Figure 3) and participants currently on treatment.

Accessibility of Liver Clinics was an important issue when considering going on treatment for 58% of participants, while 48% indicated that clinic location was not a challenge to staying on treatment.

FINDINGS FROM THE GP AND SPECIALIST PHYSICIANS STUDY

Over 90% of GPs had been involved in the health care of patients with hepatitis C. Most GPs had diagnosed a patient with hepatitis C with almost half 'often' or 'very often' recommending a patient to have a test for hepatitis C. The most common situations which prompted GPs to test patients for hepatitis C are: history of incarceration, history of IV drug use, elevated ALT level over a period of 6 months, followed by having a partner with hepatitis C.

Time of diagnosis was the time most Specialist Physicians preferred to receive a patient referral (58%), which matched the time most specialists received patients (59%). Specialist physicians considered it too late to receive referrals once a patient develops symptoms and when a patient develops signs of chronic liver disease. Specialists rated the greatest hindrances to effective treatment to be a late referral, patient's drug use and treatment non-compliance.

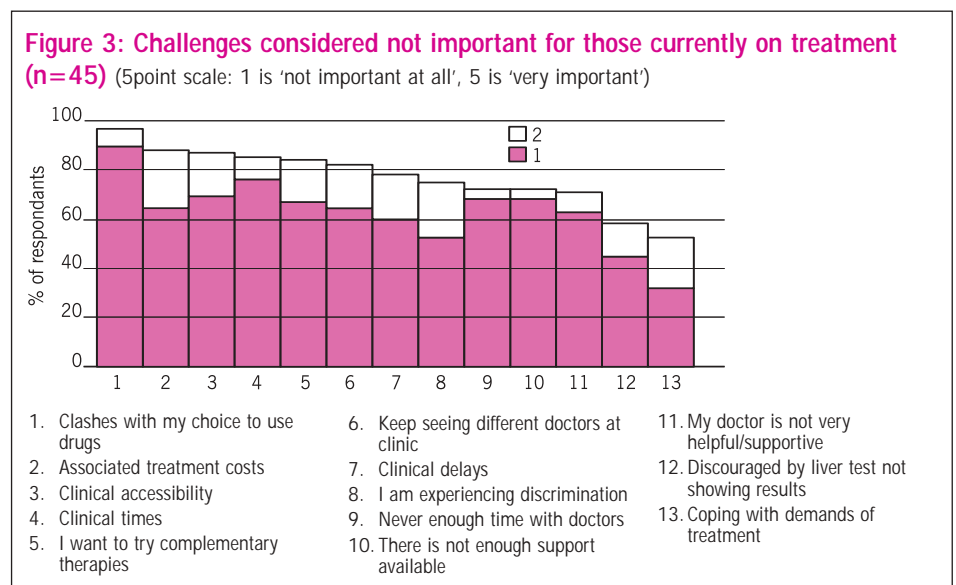
However, the study noted that GPs and Specialist Physicians were not always consistent in referral patterns. For example, 74% of Specialists were happy to accept a referral from a patient who currently injects, while a much smaller percentage of GPs (51%) were likely to refer a patient to a specialist who is currently using. A patient requesting a referral was rated high by GPs as a reason to refer a patient, while only 28% of specialists stated that they would like to get a referral based on a patient's requests.

These findings highlight the need for GPs to be informed about treatment options for patients with hepatitis C, and certainly for GPs to be aware of Specialist Physicians requirements in terms of the optimum time for referral.

CONCLUSIONS

These findings show that treatment issues such as success rates, side effects and having the support of the medical profession are crucial to enhancing not only access to treatment but also to staying on treatment. Further findings from the study will be available on the Hepatitis Social Research Program website, accessed through www.latrobe.edu.au/arcshs from early 2005.

In the meantime, further information about the study can be directed to Stephen McNally at s.mcnally@latrobe.edu.au.



TREATING HEPATITIS C INFECTION EARLY IN CURRENT INJECTING DRUG USERS

OANH NGUYEN, NICK WALSH AND MARGARET HELLARD

EPIDEMIOLOGY & SOCIAL RESEARCH PROGRAM

THE MACFARLANE BURNET INSTITUTE FOR MEDICAL RESEARCH AND PUBLIC HEALTH

APPROXIMATELY 240,000 AUSTRALIANS HAVE BEEN INFECTED WITH THE HEPATITIS C VIRUS, WITH AN ESTIMATED 16,000 NEW INFECTIONS OCCURRING EVERY YEAR. AROUND 90% OF ALL NEWLY ACQUIRED HEPATITIS C INFECTIONS IN AUSTRALIA OCCUR AS A RESULT OF INJECTING DRUG USE (IDU).

Although it is difficult to accurately measure, research studies estimate that between ten and twenty percent of current IDUs become newly infected with hepatitis C every year.

Approximately 25% of people infected with hepatitis C naturally clear the virus within 12 months after they are infected. The majority of people, however, do not manage to clear the virus naturally and have ongoing or 'chronic' infection. Most people do not experience any symptoms when they are first infected with hepatitis C. There are many things we don't yet understand about early hepatitis C infection, including why some people naturally clear the virus while others go on to develop chronic infection.

There are different types of hepatitis C virus, which are known as genotypes. The most common in Australia are genotypes 1 and 3. It is possible to be infected with more than one genotype of hepatitis C; it is also possible for a person to become reinfected with hepatitis C even after they have naturally cleared their hepatitis C

infection. At present, we do not understand who is at high risk of multiple genotype infections or of re-infection.

In Australia, treatment is largely only available to people with chronic hepatitis C infection. This treatment consists of a combination of pegylated interferon and ribavirin. People who are infected with genotype 1 are treated for 48 weeks, while those infected with genotype 2 or 3 are treated for 24 weeks. Treatment is deemed successful if a patient has no evidence of the hepatitis C virus in their blood six months after the end of treatment (called a sustained virological response or SVR). The likelihood of having a SVR is about 40% for genotype 1 and 70% for genotypes 2 and 3.

Treatment has generally not been available in Australia for people who have been recently infected with hepatitis C. A number of research studies over the past few years, however, have suggested that early treatment (in the first year or two after infection) may increase the chances of a person clearing the virus compared with being treated for chronic hepatitis C infection. The level of SVR in these studies has varied from 70% to greater than 90% for all genotypes. As these studies were small with relatively few patients and even fewer current IDUs, however, further research is needed to better understand who would benefit from early treatment of hepatitis C. Improved information is also needed to understand who is more likely to naturally clear their hepatitis C infection, when is the best time to offer "early treatment", if current IDUs can be successfully treated without any major side effects from treatment, and whether they can remain uninfected after treatment has finished.

In an effort to answer some of these questions, the University of New South Wales (UNSW) and the Burnet Institute (Melbourne) have initiated a 5 year research study, known as the Australian Trial of Acute Hepatitis C (ATAHC). As there is uncertainty surrounding the benefit of treating people in the early stages of their hepatitis C infection, this study aims to answer this important question. The study will follow the natural history of acute hepatitis C and, through offering treatment to participants who have recently been infected, will measure if treatment is effective in clearing the virus in the early stages of infection. The study also aims to improve the management of people recently infected with hepatitis C through improving our understanding of why some people naturally clear their infection while others go on to develop chronic disease. In the long run this may assist in the development of a hepatitis C vaccine.

The Burnet Institute recently commenced recruitment to the study and is looking for people who have been diagnosed with hepatitis C in the last six months and who think they became infected in the past two years (the full study recruitment criteria are listed below). Participants then have the choice of being treated with pegylated interferon for six months (given as a weekly injection), or to go into the non-treatment arm of the study. The study will follow all participants for three years, comparing the treated and untreated groups of participants. Currently, pegylated interferon is only available to people with chronic hepatitis C infection who have evidence of liver damage.

Current and past IDUs are encouraged to participate in the study.

AND NOW INTRODUCING THE HEPATITIS SOCIAL RESEARCH PROGRAM...

STUDY RECRUITMENT CRITERIA

In order to qualify for the study, candidates **MUST** meet all of the following:

- Have had their first positive antibody test for hepatitis C within the past 6 months

AND

- Had either a negative hepatitis C antibody test anytime in the 2 years prior to that

OR

- Had an episode of unexplained hepatitis in the year before their first positive antibody test [documented jaundice and/or raised ALT (>10 x ULN)]

FOR MORE INFORMATION ABOUT THE STUDY IN MELBOURNE, PLEASE CONTACT THE FOLLOWING PEOPLE:

Oanh Nguyen	(03) 9282 2174
Margaret Hellard	(03) 9282 2163
Nick Walsh	(03) 9282 2261

The ATAHc study is funded through the US-based National Institutes of Health (NIH) and the pegylated interferon is being supplied by Roche Pharmaceuticals.

The study has been approved by all the appropriate human research ethics committees in New South Wales and Victoria in accordance with the National Health and Medical Research Council guidelines

The newly configured Hepatitis Social Research Program based at the Australian Research Centre in Sex, Health and Society (ARCSHS), La Trobe University endorses a collaborative, public health approach to (mainly) hepatitis C research, education and training and policy development.

Research projects currently in progress include:

- **Now, later or never: Challenges of hepatitis C treatment.** Dr Stephen McNally, Dr Meredith Temple-Smith and Professor Marian Pitts
- **Discrimination or discretion: factors contributing to the discrimination of people with hepatitis C in health care settings.** Dr Meredith Temple-Smith and Dr Karl Jenkinson
- **Contraceptive use in women with hepatitis C.** Anna Olsen, PhD student

The team also includes Judith Jones, longtime community educator and editor of the National Hepatitis C Resource Manual. Judith co-ordinates the pre-and post-test HIV and hepatitis C counseling training programs and BBV continuing education. Community Liaison Officer Sue Dyson will also be assisting the Program to communicate research results to a range of practitioners, services and policy makers.

The ARCSHS Hepatitis Social Research Program results from a re-organisation of the former Hepatitis C Social Research

Program at Deakin University, which from the mid 1990s until 2003 was led by Professor Sandy Gifford. This was a collaboration between researchers at ARCSHS, Deakin and the Australian National University, along with clinicians and community organisations.

ARCSHS has become the new hub for the Hepatitis Social Research Program since Sandy Gifford transferred to LaTrobe University at Bundoora to establish and direct the Refugee Health Research Centre. Sandy still retains an interest in hepatitis C in newly arrived refugee communities and is chief investigator on the NHMRC-funded Discrimination Project, along with Dr Mary O'Brien (now at Melbourne University) and Dr Jan Browne. Other former Deakin members have re-located: Meredith Temple-Smith to ARCSHS and Dr Mark Stoové to Turning Point Alcohol and Drug Centre (under its new director Dr Nick Crofts), from where he will continue to collaborate with the Hepatitis Social Research Program.

Readers of the Good Liver who have already participated in the earlier studies such as Women Living with Hepatitis C and Men, Health and Hepatitis C will be pleased to know that information from these studies will be part of the program's new website which will be functional from early 2005, and which will be accessible via the ARCSHS website, at www.latrobe.edu.au/arcshs/.

TREATMENT STUDY

A Treatment Study for people with hepatitis C who have failed to clear the virus after treatment with Interferon and Ribavirin.

The Alfred Hospital and Monash Medical Centre are involved in a new study using PEG-Intron and Ribavirin to treat people who have had previous Interferon and Ribavirin for at least 12 weeks and still have the hepatitis C virus detectable in their blood.

The duration of treatment will depend on response, but could be for up to 5 years.

For more information or to see if you would be eligible for this treatment program please call either Caroline Day (The Alfred Hospital) on 9276 2223 or Sherrylene Warner (Monash Medical Centre) on 9594 5545.

SEXUAL TRANSMISSION OF HEPATITIS C. NEW RESEARCH SHOWS NO RISK?

PETER HIGGS
EPIDEMIOLOGY AND SOCIAL RESEARCH
PROGRAM, THE BURNET INSTITUTE

Regular readers of the Good Liver will no doubt be aware that Hepatitis C is not classified as a sexually transmitted infection in Australia. They will possibly also be aware that there have been an enormous number of studies looking at this issue and the risk of transmission has ranged from almost nil right through to 30%. Almost everything we hear or read advises that the risk of sexual transmission for HCV is low, especially in monogamous heterosexual couples. But what does low really mean?

Several recently published papers¹ continue the on-going debate as to whether or not Hepatitis C can be transmitted sexually. If anyone wants a copy of these papers they are available from the Council.

This short discussion goes over some of the most recent findings from the scientific literature in regards to sexual transmission. Unfortunately nowhere in these studies is there a definitive NO RISK but as you will read there are so few cases of HCV acquired in this manner reported that we can be confident in saying that sexual transmission of HCV is a very rare event. In all circumstances it must involve blood.

The first thing to say is that there will continue to be on-going research into this subject area and no doubt there will be more studies published in the next 12 to 24 months which may be contradictory to the research findings.

The studies below were all quite different in design and the characteristics of the participants. Just briefly here is some of the general information about the each of the studies.

VANDELLI ET AL., 2004

Vandelli et al., 2004 was an Italian study that followed 895 monogamous heterosexual partners of individuals who were positive to HCV antibodies and also PCR positive over many years. Over 85% were followed for ten years with the other fifteen percent lost to follow-up or excluded

because of a sexual relationship outside of the relationship. A little over 3% were not followed because the partner was found to be already infected with HCV at the start of the study. All the couples participating in the study denied practising anal intercourse, or sex during menstruation or condom use and reported sex almost twice weekly.

At enrolment to the study in 1991 the average age of participants was 45 years (range 18-65 years) and they had been married for an average of 23 years. Males made up about 60% of the index cases, that is they were the ones infected with HCV.

In this study there were just 3 HCV infections reported during the 10 years of follow up (one in years 7, 8 and 9 of the study). However in one couple the genotype was totally different (2a compared to 1b) and in the other two although the genotype was the same further analysis showed that each partner carried a different actual virus excluding the possibility of spousal transmission. In summary, this study concludes that sexual transmission is a very rare event.

HAMMER ET AL., 2003

Hammer et al., 2003 was a retrospective American study which measured the risk of sexual transmission of hepatitis C virus (HCV) in a sexually active adult population in San Francisco. In this study the sexual behaviours and HCV antibody status were measured in persons who sought repeat anonymous testing for HIV in San Francisco from October 1997 through to March 2000. The study had 981 repeat testers with the average length between tests being 9 months, and the HCV antibody prevalence rate in the sample was 2.5%.

The study found that among men who have sex with men who denied injecting drug use (three quarters of the sample) the factors associated with them having HCV antibodies at the start of the study included being older than 50 years, having HIV infection and being non-white. Having HCV antibodies was not found to be associated with sexual risk behaviours. There were no HCV seroconversions reported in the study, whereas in the period of the study 6 new

herpes simplex virus-2 infections and 10 new HIV infections occurred.

The authors conclude that the absence of new HCV infections in this sample supports the hypothesis that the risk of sexual transmission of HCV is very low.

BOOYARAD ET AL., 2003

Booyarad et al., 2003 was a Thai study that recruited 160 people who were HCV RNA positive (which means they had ongoing HCV infection) attending two hospitals in Bangkok in 2001. Men made up 2/3 of the sample with an average age of 53 and conversely women made up 2/3 of the spouse sample with an average age of 48. Couples had been together for an average of 23 years. HCV antibodies were identified in the partner of 4 of the 160 couples but only 3 of them had HCV RNA. All of these 3 had been exposed to potential sources of HCV infection other than through interspousal transmission; two had blood transfusions over 20 years previous and one serious medical operation 15 years previous. They also all had different genotypes of HCV ruling out infection by their partners.

These three studies all provide further evidence that sexual transmission is low. The authors in all studies state that it is unnecessary to recommend condom use for HCV prevention in long term monogamous couples.

So in a nutshell the latest research from three different countries, using three different research methods all lead to the same conclusion - HCV and sex are not linked.

REFERENCES:

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THE PATH LESS TRAVELLED: FINDING HEPATITIS C SERVICES IN RURAL VICTORIA

MEREDITH TEMPLE-SMITH
AUSTRALIAN RESEARCH CENTRE IN SEX,
HEALTH AND SOCIETY

MARK STOOVÉ
TURNING POINT DRUG AND ALCOHOL
CENTRE

'[I] have no access to specific hep C treatment or hep C doctor. They are not in our region. The closest is in Geelong, I'm...three and half hours away. Sux!'

This is an example of what life can be like for some of the 7,500 (or 19.6 %) Victorians with hepatitis C who were resident outside metropolitan Melbourne when their hepatitis C status was notified in 2002. But is it the case for all rural residents with hepatitis C?

Although there are still some serious limitations, hepatitis C services in rural Victoria have improved over the past decade. The situation is generally better where there are larger agencies to foster education and health promotion and more numerous places where individuals can assist those with hepatitis C. Often, particularly in smaller communities, hepatitis C services are supplied by organisations that are not specifically mandated, or funded, to do so.

The report '**Casting the Net: the Challenge of Locating Hepatitis C Services in Rural Victoria**' aimed to provide a snapshot of current hepatitis C services in non-metropolitan Victoria. This study sought to locate the hepatitis C services in rural Victoria which could easily be identified and accessed by a person affected by hepatitis C. This search was not exhaustive and did not include services that were part of an indirect referral pathway. Rather services were sought which could be accessed by a person without special knowledge of the health care system.

Rural research officer, Shelly Nevins, identified and contacted key agencies within rural regions that could be accessed by those with hepatitis C. A total of 59 staff members working in a variety of areas within these agencies were interviewed about the hepatitis C services available in their region. It was often a complex process identifying the key people, which suggested that rural residents with hepatitis C may also experience difficulties locating the same agencies and individuals to access services, particularly if they were concerned about confidentiality.

WHAT DID THE STUDY FIND?

While it was evident that there were many gaps in services, the study highlighted the fact that geographical isolation alone does not account for presence or absence of services. A distance of 300km means far less to someone with a decent vehicle and private health insurance, than 100km does to someone with no car and no insurance. The Hepatitis C Council of Victoria has long emphasised the importance of not imposing metropolitan models on rural communities. Population density, size, and distance from Melbourne are not a good guide to the rural experience, because many local variables (eg., cost of petrol, condition of roads, availability of transport, etc) have a strong bearing on how isolated people feel.

We found that a range of factors affect the provision of services and access to support and treatment in Victoria. Key issues included the desperate need for regional liver clinics and funding to support staff offering ongoing health education and information. Locating a general practitioner with knowledge of hepatitis C was often extremely challenging. There appeared in some areas to be a lack of communication, collaboration and coordination between workers employed in the alcohol and drug and blood borne viruses sectors. Many of those interviewed commented on the need for ongoing professional development in the area of hepatitis C care. The role of local councils in supporting initiatives is crucial.

Where the need for hepatitis C services was designated in the municipal health plan there appeared to be a positive and effective response to hepatitis C. Where there was not, the response to hepatitis C was left to local services which may be struggling to manage without the support of local councils. It is probably also true to say that existing services would be utilised more by those with hepatitis C if they felt comfortable doing so, and were certain that they would perceive no discomfort or discrimination.

So, the good news is that in some parts of rural Victoria, limited hepatitis C services are available and utilised. The costs for clients, however, may be prohibitive, and the fact that many complementary medicines are not eligible for funding under the Pharmaceutical Benefits Scheme limits the choice of those with chronic hepatitis C. Nonetheless the situation is far better than it was 5 years ago. Some thanks for this is due to the Hepatitis C Council of Victoria, who employs two workers who are dedicated to supporting workers in rural health and people with hepatitis C in rural Victoria. These workers face tremendous challenges in servicing diverse communities, particularly where large distances are involved and there is great variation in the breadth and quality of community health services. This study underscores the need, identified by the Council, to build workforce capacity and enhance the capability of local regional agencies to provide hepatitis C services. The workforce and capacity building theme is being emphasised in the Council's new strategic plan. Hopefully in 5 years time, a replication of this study will find many more accessible hepatitis C services in rural Victoria.

'Casting the Net: the Challenge of Locating Hepatitis C Services in Rural Victoria'

*Meredith Temple-Smith, Shelly Nevins, Maria Platt, Mark Stoové, Sandy Gifford
School of Health Sciences, Deakin University, September 2003.*



my life in the medical system...

Well I have just come home from our support group meeting and decided to sit down and write 'my hep C story'.

I have had the virus since way back in the Non A/Non B days but since I didn't know of its existence then, what it was called didn't really matter. By the time I was diagnosed it was called hep C and I still knew very little about it.

I was told I had the virus by a fantastic doctor who spent a long time with me explaining it and what I could and couldn't do. There should be more doctors like her. She referred me to a gastroenterologist and my life in the Victorian medical system really got going. I saw him once a month and gave him lots of blood and in return he gave me a biopsy and casually mentioned I had cirrhosis. Once again my ignorance was bliss, although I did think at the time 'that doesn't sound so good.'

He talked me into going on treatment and whilst he explained about the potential side effects, he did not over emphasise them. Now I have learnt more, it really annoys me that so much is said about the terrible effects of biopsies, treatment and the virus itself. Of course the potential is always there, and I do know many people who have gone through hell on treatment, but it is not always the case. It is rarely mentioned that some people experience very few or no effects at all. Everybody is different and the effects can never be the same for everyone. Certainly you should be aware of what might happen, but don't assume it will be the worse case scenario, you can always stop treatment if it does hit you too hard.

Anyway enough of the sermon - back to the story.

The biopsy procedure itself was fine, he had got it in one go. I have heard that sometimes they miss the first time, although I'm buggered if I know how they can miss something as big as a liver. The treatment itself was OK, but with other factors, the treatment process turned out to be a bit of a problem. I am an epileptic and the medication I was on gave me a bad tremor in my hands. After being shown how to inject myself by sticking a needle once into a rubber ball (I think it is assumed that everyone who has hep C has had previous experience with self injecting and so once is enough) I was left to go solo and that's when the fun started. Trying to stick a needle into your stomach when your hand is jumping about is not an easy thing to do. Quite soon my stomach was a mass of bruises and I was dreading the next injection. Then salvation occurred. The gastroman I had been seeing went on holiday and a new gastro took over. She greeted me with the results of my last lot of blood tests facing me on the desk. I had never seen any results before, but she told me that some of her patients liked to see them and proceeded to explain what the various things were. She even asked me if I had any questions!

After a couple of visits she took me off the treatment. When I had finished kissing her feet and groveling my thanks, she explained that with the problems I was having with injecting (and the bruising

which took nearly four weeks to disappear) the treatment seemed to doing me more harm than the virus.

At that stage I was probably in as bad a shape as I have ever been. During treatment, I had been 'just' working. But not long after this I spent ten days in hospital with exhaustion and haven't worked since. That, coupled with treatment, the epilepsy medication and of course, the virus itself had made me very unwell indeed.

After a few more visits she explained to me fully the state of my liver and the effect it was having on me. She wanted me to do a 'work up' for a liver transplant. As I had gained a lot of respect for her I agreed. The 'work up' consisted of spending about a week in hospital giving litres of blood, talking to psychiatrists and counsellors and being subjected to every type of scan and scope known to the medical world, plus a few extra they made up for the occasion (well it seemed like it at the time anyway).

I had the impression all this was really just exploring what stage my body was at and that the transplant was not actually being seriously considered. Therefore I was not too fussed about the whole thing and when I was told I did not need a transplant at that time I simply thought 'yeah OK well it was an interesting experience anyway and I had a bit of fun.' It wasn't until fairly recently that I found out I would have been putt on the transplant waiting list. Glad I didn't know that then!

Well since then I have been getting along quite well with only one little problem along the way. Around the time I stopped working, I had begun to experience dizzy spells and double vision. This got much worse under certain conditions until finally I collapsed. I didn't actually black out, I just completely lost balance and couldn't stand up. I found this to be a bit disturbing. When it happened again I went to hospital and was given several tests before being sent home a couple of days later. However, I fell over two or three more times until finally falling on my face, on bitumen. Luckily I was with a friend who was sensible and knowing my medical history, took me to the hospital I usually went to.

ORGAN DONORS SAVE LIVES

After my face had been cleaned up and sutured, the tests started again. In one week I saw twelve different doctors who would come in, look thoughtful, perhaps throw a few Latin words in for colour and then walk away. By the time they were ready to get rid of me one practically admitted they did not know what was wrong and another brightly suggested I should think about a walking frame! It never occurred to them, even after I suggested it, that perhaps all the medication I was taking (nineteen pills a day) was simply not getting cleaned out of my system due to the poor condition of my liver.

I decided to see my neurologist and get his opinion. He checked me out and thought there may be some injury to my brain stem. However, he first wanted to drop my medication quite a bit and see what sort of effect that would have. Over time we did this and to my delight the falling, the dizziness and the double vision stopped. Even the tremor I had in my hands disappeared. It seems I was simply overdosing on my medication.

One last thing before I finish.

Around this time I joined the support group at the Hepatitis C Council because I wanted to be able to talk to people openly about my hep C without fear of any discrimination and in an atmosphere of real understanding. The support, information and advice I have received there has done more to help me through the past few years than any other single factor. So if you have never been to a support group meeting, get in touch with the Council and come along and see what you think. It may be just what you need.

And to Pier (who is the convenor of the group) and to all the other staff at the Council who have helped me so much, my thanks.

Mark

AUSTRALIA HAS ONE OF THE WORST ORGAN DONOR RATES IN THE WESTERN WORLD AND IT'S TIME WE DID SOMETHING ABOUT IT!

Slightly over one in ten people in Australia have registered. Apathy is illustrated by the large percentage who never get around to it, although most are sympathetic to our cause.

SOME FACTS AND FIGURES

- In Spain, France, Singapore and the Scandinavian countries, the exception is the rule. You are presumed to be a donor unless you make the effort to exclude yourself.
- Throughout 2003, over 600 life-saving transplant operations were performed. Sadly during that year many people died while waiting for an organ transplant.
- 2,000 people in Australia are on a transplant waiting list - 1/3 of them Victorian.
- 120,000 Australians die each year in circumstances that would allow organ retrieval.
- As many as 10 people can benefit from organ and tissue donation from 1 person.
 - > Organs: kidneys, lungs, heart, liver, pancreas.
 - > Tissue: corneas, bone, heart valves, skin.
- Transport: Organs will last outside a body for - heart 4 hours, lungs 10 hours, liver 8 hours, pancreas 12 hours, kidneys 24 hours, and corneas 5 days.

TRANSPLANT SUCCESS RATES

In Australia, patient survival rates, 1 year after receiving a transplant are:

- Over 90% for kidney, heart, pancreas and corneas;
- Over 80% for livers; and
- Over 70% for combined heart/lung and lung only transplants.

TRANSPLANT WAITING LISTS

Organ	Number on waiting list	Average waiting time for transplant
Kidney	1490	3.8 years
Heart	70	2.2 years
Heart/Lung & Lung	112	1.2 years
Liver	78	1.5 years
Pancreas	35	1.7 years

ANZDATA Stats as at Jan 2003

WHAT CAN YOU DO:

- We are all going to die. Your death, my death, could save the life of someone else.
- You are many more times likely to require an organ transplant than ever become a donor!
- THINK about offering to become an organ donor. TALK about it with family and friends and when you've made the decision, TELL your family.

WHO TO CONTACT:

The Victorian Organ Donation Service 'LifeGift' coordinates organ procurement, provides counselling to donor families and assistance to hospitals to establish organ donor review and referral systems.

CONTACT THE LIFEGIFT COMMUNICATION ADVISER - (03) 9349 4762 OR VISIT THE WEB SITE AT: WWW.ORGANDONOR.COM.AU



this virus no longer scares me...

I thought I would write this story before I receive the final results of my recent treatment. I only just finished last week, had my final blood test, so I'm still awaiting the results.

I thought I would write now, because right now it doesn't worry me at all on the health side, that I have hep C, so the end result, positive or negative won't bother me at all on the health issue. I have learnt so much, that this virus no longer scares me.

What does still bother me is the stigma that is attached to this virus. I know what it is like to smugly sit on the other side of the fence and make assumptions about diseases and viruses that I know little about.

Let me finally start with my story. I am a divorced 45 year old mother of 3 young children, extremely conservative, bordering on boring. An unlikely suspect for anything hideous.

I went to see my local doctor in an affluent beachside suburb with some pains radiating down my arm. I had been healthy and active. Knowing that I'm the sole carer for my kids, the doctor was extra careful and ordered all sorts of scans, ultrasounds and blood tests. After a couple of weeks, I got a call from the doctor at work. The blood results had been double-checked and the results finally confirmed. They informed me that I had Hep C and it would be a good idea to see a specialist. They also told me that under the Health (Infectious Diseases) Regulations, they had to notify the authorities, the Health Dept of Victoria etc etc.

'Does the health department post a warning sign up on your front door?'

They kept saying how sorry they were, how sorry...I had suddenly turned into a leper. I went into shock. I just about threw up at work. I didn't know anything about these viruses; after all, I'm a boring suburban pillar of the community type mother. I sat at my desk, thinking, "Is this the deadly virus that Pamela Anderson has, where she will die within years?" Is this very contagious, after all I had helped out at the school canteen? Does the Health Dept post a warning notice up on my front door? Who will look after my kids? Will they be contagious too? I felt so sick, that I packed up my desk, and went home early.

I got straight onto the Internet at home and that made me even sicker. I looked up info, mostly American treatment plans and personal stories and they were full of horror. There were different genotypes, statistics, treatments, deaths, and very few positive stories. I printed off pages and pages of info, until I was confused with too much medical jargon. The treatments actually sounded worse than the disease. However, the main positive thing I learnt was that I would not die in a few years, which was a relief.

I went to see a specialist who was very calm and casual about the virus. He made me see hope, that I could live with this and would probably die of old age. None-the-less, we thought a liver biopsy would

be a good idea as I had lived with the virus for about 28 years. When I had been a rebellious 17 year old, my older boyfriend had introduced me to heroin on a number of occasions. When we broke up, the habit had been left behind in my past life. I went on to study and have a successful career, a happy and healthy life...at least I had thought so...

The biopsy was performed on Friday; I rested for a couple of hours, and then went home. No problems. Luckily, the biopsy showed minimal damage, which was a relief for me, as I had worried about the length of time. The damage wasn't severe enough for Govt subsidized treatment, however I was able to participate in a clinical trial at the Alfred Hospital. Even at this stage, I was no longer scared of the health issues. I had called the helpline and spoken to a very calm person. The Australian Hep C Council had provided information that had been very reassuring, but as a single woman, I wanted to be able to say honestly to potential partners that I was disease and virus free.

Why?...Because I knew that a couple of months ago, if a potential partner had been upfront with me and told me that they had hep C, I would have run a thousand miles, due to my ignorance. I wouldn't have taken the risk. I look back now, and can see what an ignorant idiot I was; unfortunately, the majority of people are still like that.

'the specialist was very calm - he made me see hope, that I could live with this and would probably die of old age'

So, the date was set, I would begin a new treatment, of daily tablets and a weekly injection. With tears I told my kids that mummy was sick, and that I would be having treatment that made me sicker, but I would be ok at the end of it all. We all had a good cry and the kids promised to help more around the house. I didn't tell them what it was, in fear that they would tell their friends and we would all be treated like lepers. I didn't even tell my girlfriends, but I did tell my boss who was a family friend, as I knew I would have to take time off work to go to the hospital, .

and according to the majority of info available, I would probably be sickly. He was cool about it, and just asked how I got it. He was more shocked by the fact that I had a "past" life.

I actually ended up telling one of my girlfriends. In confidence, she told me that she had just caught genital herpes. I felt so sad for her, as she was stuck with it forever, was contagious and had obvious symptoms. I actually felt lucky, that I only had hep C and I could do something about it, wasn't sexually contagious and had no symptoms. Anyway, she was very cool about it, in fact she told me that she had 2 other acquaintances with it. Once again, she was more shocked that I had a "past" life.

So far, no bad reactions from anyone, but I'm still cautious.

Treatment begins. Week one, I planned a quiet weekend and takeaway food just in case I was nauseous and irritable. As it turned out, I had a bunch of interstate relatives lob up and stay a week. No problems, in fact I felt so energised. Was it because the treatment was working or that I felt I was doing something positive? The weeks continued in the same positive energetic manner. Where were all these dreadful side effects? Oh my gosh, was that cold sore due to the treatment? I hadn't had one of those for years.

I waited for more bad side effects. Ok, I did get a few headaches, and after a period of time, I had trouble sleeping on some nights (for which I took the occasional sleeping tablet). I did become a bit forgetful and confused by pathetically minor details (did I mention that I'm a Virgo and we DO NOT make mistakes...ever) Well I made 2 beaut mistakes at work during the 4 months of treatment.

As always, I looked for the positives. The medical staff told me that on average most people lose about 10% of their body weight. I focused on that. Great, at 85 Kg, I could do with a weight loss. I was already imagining my healthier thinner self. Well, after 4 months, I'm still 85 kg, so I have complained to the medical staff about deceiving me. I really had my hopes up. (I'm a typical woman after all!)

'I've done my best and faced up to my deep dark past'

So, I have decided to write to others, to give hope that it is not as bad as you think (except for not losing weight). The virus itself is not scary, nor is the treatment. The number of times I sat in the hospital waiting room, waiting for my turn, I was observing others in the room. They all looked so normal. No one in the room looked sickly, in fact they all looked just as healthy and conservative as me!

I could have started off with a better attitude and outlook, but what set me off on this presumed tale of horror, and gave me grief, was the ignorance of my initial source of info, my local doctor. I just remember the many sympathetic sorrys, and receiving the news over the phone while at work. This doctor had obviously failed their psychology class, as we all know you don't ring people up to give them bad news over the phone! Suburban doctors need to be more aware of the true facts and success rates of hep C and not spread doom and gloom.

So, whether the final results show that I'm clear or not, I'm happy. I've done my best, I've learnt a lot about viruses, not just hep C and I've faced my deep dark past and come out a better person. I may even tell a few more people, as the reactions hadn't been too bad after all.

Brenda

P.S. My initial pain down my arm turned out to be tennis elbow...now that is funny!!!...and it's all better now

SUPPORT GROUP BREAKING THE CHAINS

HIV | HEP C SUPPORT & EDUCATION GROUP - WARRNAMBOOL

Breaking The Chains is a Warrnambool and district group of HIV or hepatitis C positive people, their friends, families and supporters. We meet on the 2nd and 4th Thursdays of every month.

For further information or meeting details, please contact Jeffrey on
9486 5972 or **040 124 0167**
or email: breakingthechains@hotmail.com

HEPATITIS C AWARENESS WEEK 2005

Exciting & important news!!

THE HEPATITIS C AWARENESS WEEK HAS GONE NATIONAL, AND TO BEST ACCOMMODATE ALL STATES AND TERRITORIES, THE WEEK WILL NOW TAKE PLACE FROM MONDAY 23 TO FRIDAY 27 OF MAY

THE THEME FOR THE 2005 AWARENESS WEEK IS TREATMENT.

The Australian Hepatitis Council will be supporting the Week with a national media strategy, a national launch, a national website and printed materials.

In conjunction with these resources, the Victorian Council will be repeating our statewide community involvement strategy, including our own launch and a few select events. We invite you to be involved, so please put the dates in your diary now.

IMPORTANT REQUEST! HELP NEEDED FOR MEDIA CAMPAIGN

AS PART OF THE MEDIA STRATEGY THE AHC IS LOOKING FOR PEOPLE IN EACH STATE TO TELL THEIR TREATMENT STORIES TO VARIOUS AUDIENCES. THEY WILL PROVIDE SUPPORT AND TRAINING FOR THIS.

IF YOU ARE INTERESTED IN HELPING, OR GETTING MORE INFORMATION - PLEASE CONTACT HEATHER AT THE VICTORIAN COUNCIL ON 03 9380 4644 OR EMAIL heather@hepcvic.org.au.

CAN MUSHROOMS HELP YOU SURVIVE LIVER CANCER?

JIM ARACHNE
COMPLEMENTARY THERAPY TREATMENTS
OFFICER, VICTORIAN AIDS COUNCIL

Current medical treatments for people with hepatitis B or C who develop liver cancer are far from ideal and survival is poor. Now, a simple mushroom extract has been shown to dramatically increase survival from this cancer and to reduce its recurrence.

Many mushroom species, such as shiitake, reishi, maitake and coriolus, have been used as food and medicinally for centuries in China and Japan. A hybrid shiitake mushroom has been developed at the Pharmaceutical Sciences faculty of the University of Tokyo and, in 1987, a specific compound, called "Active Hexose Correlated Compound" - or AHCC for short - was isolated from it. Early research on AHCC in the 1980's focussed on its effects in regulating high blood pressure. Since then many other trials have been completed - mainly focussing on AHCC's effect on immunity and in the treatment of cancer.^{1,2,3}

In 1992 a further trial was begun to examine the effect of AHCC on the survival of people with liver cancer. From February 1st that year all patients at the Kansai Medical University in Japan who had had surgery for liver cancer were considered. Recruitment continued until a total of 249 consecutive patients had been invited to participate in the trial.

Of these 249 patients 227 (91%) had hepatitis B or C with 22 (9%) having no evidence of current viral hepatitis infection. The majority, 169 (68%), had hepatitis C and 58 (23%) had hepatitis B. 105 (42%) had cirrhosis.

After surgery, 222 suitable patients were offered treatment with AHCC. Of these, 113 began treatment and took 3 grams daily of AHCC. The remaining 109 patients served as controls.

Because of this method of recruitment into the trial, ie. patients freely chose whether or not to take the AHCC, the possibility was raised that those taking the AHCC might be significantly different than those who refused it. However, this was shown not to be the case. Of 48 different characteristics examined between the two groups [e.g. ALT, AST, size of tumour, type of viral Hepatitis etc] only two were different. These were platelet count and albumin. These two factors were worse in the AHCC group.

RESULTS:

A five year follow-up showed that people taking the AHCC had a clear advantage. The AHCC more than halved deaths in the patients who took it. 23 (20.4%) people taking the AHCC died versus 51 (46.8%) [p= 0.003] in the control group. The cause of death in both groups was recurrence of liver cancer in over 90% of cases.

The recurrence of liver cancer was nearly halved in the group taking the AHCC with only 39 (34.5%) people developing cancer for a second time versus 72 (66.1%) [p= 0.03] who developed cancer again in the control group.

AHCC showed no side-effects. However, three people decided to stop taking it due to slight nausea. Generally, AHCC seems free of side-effects. A basic review of clinical research into AHCC stated that; "No negative side effects or drug interactions with AHCC have been reported during the history of its use(5)."

COMMENTS:

This is clearly a credible and important trial - for the following reasons;

- It measured effectiveness in terms of reappearance of cancer and of death rates - not just lowering of liver enzymes, such as ALT, or of reduction in viral load.



- Follow up was long-term - ie. up to 5 years - not just a few weeks or months to measure changes in lab markers such as ALT.
- It recruited a statistically significant large number of people - ie. it was much more convincing than a small collection of case histories.
- It showed that AHCC could affect the course of serious illness - ie. all people in the trial had liver cancer, had tried surgery to remove the cancer plus 42% had cirrhosis.

As well, this successful trial of AHCC does not stand alone. Much more research has been completed on AHCC that supports its potential as a wide-ranging therapeutic substance. For example, AHCC has previously been shown to increase natural killer cell activity in people with cancer. In laboratory animals it has been shown to reduce the formation of secondary cancers [i.e. metastases] from breast cancer (7), to increase detoxification enzymes in the liver, to protect the liver from chemical injury (8) and to prevent experimentally induced diabetes (9).

Doctors also have accumulated substantial clinical knowledge of AHCCs usefulness. It's estimated it is being used in over 700 Japanese hospitals (6).



MOVING ON

Regular readers will remember that I commenced at the Hepatitis C Council twelve months ago to coordinate the Workforce Development Initiative (WDI). The WDI targeted health and community workers and aimed to reduce levels of discrimination experienced by people with hepatitis C when accessing services in Northern Metropolitan Melbourne and Barwon South West. The project was highly successful in raising awareness in the two regions of hepatitis C-related discrimination and achieved significant strategic outcomes through the implementation of the project. Some highlights of the project have been:

- 'Good Practice' forums in Melbourne, Geelong and Wodonga to 145 health and community based workers;
- Tailored education and training sessions to 176 workers across the two regions focussed on non-discriminatory practice
- Developing strong relationships with organisations such as the Equal Opportunity Commission Victoria and the Office of the Health Services Commissioner that will continue beyond the project; and,
- Assisting organisations to build their capacity to develop respectful approaches when working with people with hepatitis C.

I'm taking up a new job in Tasmania that will keep me in contact with the Council which is great as I've really enjoyed my time working here. I've been presented with many challenges and rewarded with some very exciting outcomes from the project. I believe I'm leaving the Council at a very exciting time, where there are new possibilities and enthusiasm to reduce the incidence of hepatitis C in Victoria, and to ensure that people with hepatitis C receive equitable levels of care and support at an all time high.

David Clements
Workforce Development Initiative

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diary:

COUNCIL CHRISTMAS BREAK DATES

The hepatitis C Council of Victoria office will shut at 5pm on Thursday 23 December and re open on Tuesday 4 January. (*Need to speak to someone over that time? Call the Hepatitis Helpline - see page 17*)

TUESDAY 15 MARCH 2005 INTRODUCTION TO HEP C

Training session at the Councils office. From 2 to 5pm. For more details or to book contact Pier Moro on 9380 4644 or email pier@hepcvic.org.au.

23 FEBRUARY 2005 HOMELESSNESS, YOUNG PEOPLE & HEP C

A FREE day of training for Youth sector workers as part of the Council's Blood Oath Project. For more details or to book contact Venetia Brissenden on 9380 4644 or email venetia@hepcvic.org.au

23 - 29 MAY 2005 NATIONAL HEPATITIS C AWARENESS WEEK

The first National Awareness Week. The focus is TREATMENT. Put these dates in your diary now and become involved. Contact Heather Smith on 9380 4644 or email heather@hepcvic.org.au

9 - 15 OCTOBER 2005 HAEMOPHILIA AWARENESS WEEK

For more information contact HFA on 1800 807 173 or email hfaust@haemophilia.org.au or visit the web site at: www.haemophilia.org.au

WARRNAMBOOL BBV CLINIC

A comprehensive medical service for people affected by blood borne viruses in South West Victoria

We are specialist providers of health care and other support relating to blood borne viruses.

Enquires or appointments contact:

The WRAD Centre
26 Fairy Street, Warrnambool
or telephone 03 5560 3222



virtual library

Access Information Centre has a change of face!

The Access Information Centre (AIC) is pleased to announce the appointment of two new staff members, Liza Doyle and Jenny Stewart. To ensure the Centre's makeover was complete, the AIC website has also undergone a few modifications to enhance its ease of use and appearance.

Liza Doyle is the AIC Coordinator and has extensive experience in health education and training across a range of environments both here in Australia and South East Asia. After completing her nursing training, Liza undertook a Graduate Diploma in Health Science and has recently completed her Master of Public Health through Monash University. Earlier this year, Liza was involved in organising the 15th International Conference on the Reduction of Drug Related Harm. She has a strong interest in blood borne viruses and a belief in the delivery of health information and services that are practical, accessible and acceptable to all members of the community. Liza is looking forward to working with the community to ensure the delivery of a valuable and effective HIV/AIDS, hepatitis and sexually transmitted infections (STI) resource service.

Jenny Stewart is the newly appointed Librarian and has a background in the community health sector. Jenny has worked for over 10 years as the Coordinator of an information service, which focussed largely on issues of cultural diversity. Jenny is an enthusiastic appointee and is available to assist members of the community locate a range of hepatitis C, HIV/AIDS and STI resources and information, including conducting literature searches and the posting out of relevant information and materials.

For those unfamiliar with the Access Information Centre, it is a free statewide community resource centre for HIV/AIDS, Viral hepatitis and STIs. It is open to all members of the Victorian community and operates as a drop-in centre from Monday to Friday. The Centre is managed by the Alfred Hospital and has an extensive range of materials including brochures, books, journals, training manuals, videos and posters, including access to databases such as Medline. Jenny and Liza are available to assist visitors find information and show them how to use the AIC computers to search the Internet and the AIC virtual library catalogue.

The AIC website is user-friendly and includes easy to read fact sheets, links to related sites and the ability to check out the virtual library catalogue, including a 'request information' page. Please check out the revamped Access Information Centre website and feel free to give us your feedback. Keep a look out for regular updates on the latest information and expansion of services available. For people who are unable to visit the centre or do not feel comfortable doing so, we can answer questions over the phone, via the website or send out relevant information or resources. The AIC web site address is: www.accessinfo.org.au.

Happy surfing and we look forward to hearing from you!

Liza Doyle and Jenny Stewart
Access Information Centre

SALUS COMPLEMENTARY MEDICINE SPECIALISTS

SPECIALISING IN CHRONIC HEALTH STATES

Salus Complementary Medicine Specialists is a new complementary medical clinic recently established in Armadale.

The Clinic has a unique, multidisciplinary group of practitioners, including holistic doctors and naturopaths, who specialise in the progressive management of chronic illness. They are committed to providing the most effective and advanced care in this area, from the latest diagnostic techniques through to individual treatment options and strategies.

Salus' specialist team are highly experienced in assisting patients manage chronic illness, including Human Immunodeficiency Virus (HIV), Hepatitis C, autoimmune diseases and cancer. Complementary medicine is especially valuable for people living with hepatitis C. Certain herbs and nutrients can be employed to regenerate and protect hepatocytes (liver cells) as well as reducing symptoms including nausea, fatigue, depression, anxiety and headaches. There are also a number of supplements which can be prescribed to patients to reduce the incapacitating effects of Hepatitis C medication.

Salus' specialist team is supported by osteopaths, massage therapists and acupuncturists who provide pain management, musculoskeletal support and relaxation. In addition Salus' psychologists and counsellors can assist patients to adjust and deal with the many issues associated with living with a chronic illness.

Salus Complementary Medicine Specialists

1002 High St. Armadale, Victoria 3143

Telephone: +61 3 95008870

www.salusmedicine.com.au



An exploration of the Hepatitis Line

There is no typical profile of the people who call the Hepatitis Line as they come from all walks of life. Reliable sources estimate that at least 1% of people in Australia have Hepatitis C. Each one of those have people around them, such as friends, family, loved ones, peers or workmates; therefore, the number of people who are directly or indirectly affected by Hepatitis C is actually much greater than 1% of the population. The people who call Hepatitis Line are the everyday, ordinary people who may know little about the virus, and who are concerned about the medical and social implications of Hepatitis C infection.

We thought it might be interesting to highlight some of the statistics around the callers that use Hepatitis Line over the past year. Our prime mission of respecting and maintaining confidentiality remains extremely important. We collect some basic demographics on our callers in order to improve our service and ensure that promotion and advertising of our service reaches those in need. No information is recorded which can in any way identify an individual.

GENDER

As in previous years, the gender balance remains fairly equal with the number of

females (52%) calling the Hepatitis Line slightly greater than males (48%).

AGE

The majority of calls to Hepatitis Line continue to be from people aged 30 to 39, followed by callers aged 18 to 29 and callers aged 40 to 49. Very few calls are received from people aged below 18.

LOCATION

Although Hepatitis Line provides a statewide service, the majority of callers continue to be from within the Melbourne metropolitan region. We will continue to strive to raise the awareness of our service to regional Victorian areas.

LENGTH OF CALLS

35% of calls on the Hepatitis Line are 5 minutes or less in duration. Most of the calls average from 5 to 20 minutes. Approximately 20% are of 20 minutes duration or longer.

CONTENT OF CALLS

Calls to the counselling lines revolve around a range of issues. A common issue that callers wish to discuss centres on the transmission factors for Hepatitis C, which is reflected in 47% of all calls. Other issues that were mainly discussed are as follows:

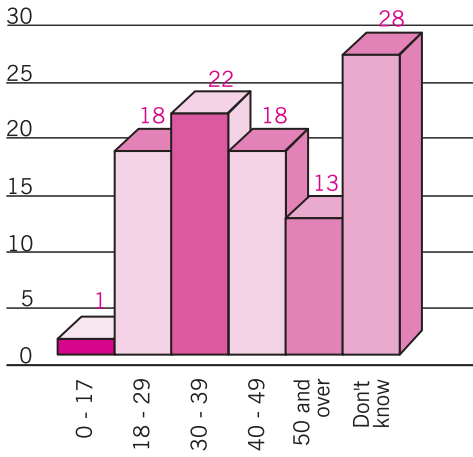
- Treatments 27%
- Symptoms 20%
- Testing 19%

Discussion about transmission sometimes involves concern about a sexual activity and whether that has placed them "at risk." Concerns about a sexual activity prompted 17% of callers to call the Hepatitis Line, suggesting the myth around the sexual transmission of Hepatitis C is still quite prevalent. Other "risk activities," which prompted callers to ring the Hepatitis Line, focussed on injecting practices (13%), casual interaction with people known or suspected of having HCV (11%) and actual or perceived contact with blood (10%).

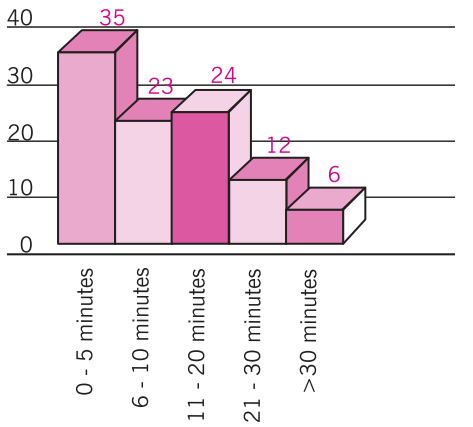
Approximately 16% of our calls involve discussion about Hepatitis A and B and many of these calls are about clarifying the differences between all these viruses.

We hope this has provided an insight into the nature of the calls we receive on the service. The prime mission of our service continues to be to endeavour to develop

AGE OF CALLERS



LENGTH OF CALLS



rapport with callers, to empower them, to help callers focus and develop their own solutions to the presented issues, and to assist callers to become aware of their own thoughts and feelings, which, in turn, enables them to be more confident about the decisions they make. For no cost at all, a call to Hepatitis Line on 1800 800 241 can provide the benefit of an anonymous and confidential service offering counselling, information and referral.

Alex Nikolovski and Ross Atkinson

**HEPATITIS HELPLINE
FREECALL: 1800 800 241**

HOURS OVER THE HOLIDAY BREAK:
The service will be shut Christmas and New Years day. Other times will be subject to availability of counsellors. Telephone counselling services will generally be available between the following hours:

Monday to Friday: 9am to 10pm
Saturday & Sunday: 9am to 11am and 6pm and 8pm.
Pre-recorded information available outside these times.

LIVER CLINICS

Albury/Wodonga

Telephone: 02 6024 5255

Alfred Hospital

Telephone: 9276 2223

Austin/Repatriation Medical Centre

Telephone: 9496 2787

Ballarat - Dr Jon Watson

Telephone: 5331 8289

Bayside Hepatitis Clinic

(through the Alfred Liver Clinic)

Telephone: 9276 2223

Box Hill Hospital

Telephone: 9895 3333

Cranbourne Liver Clinic

Telephone: 9594 3088

Epping - Northern Hospital

Liver Clinic

Telephone: 9219 8335

Footscray - Western Hospital

Telephone: 8345 6490

Geelong Liver Clinic

Telephone: 5226 7111

Knox Private Hospital

(St Vincent's Hepatitis Clinic)

Telephone: 9210 7300

Maroondah Hospital

Telephone: 9871 3371

Monash Medical Centre

Telephone: 9594 3088

Peninsula Liver Clinic

Telephone: 9781 4434

Royal Melbourne Hospital

Telephone: 9342 7212

Sale - Fitzpatrick House

Telephone: 5144 4555

Springvale Liver Clinic

Telephone: 9594 3088

St Kilda - Barkly Street Medical Centre

(St Vincent's Hepatitis Clinic)

Telephone: 9534 0531

St Vincent's Hospital

Liver Clinic: 9288 2898

Hepatitis Clinic: 9288 3580

Werribee Mercy Hospital

(St Vincent's Hepatitis Clinic)

Telephone: 9216 8633

SERVICES DIRECTORY

METRO AND/OR STATEWIDE

Access Information Centre at the Alfred

Telephone: (03) 9276 6993

Fax: (03) 9533 6324

Email: access@alfred.org.au

Web: www.accessinfo.org.au

ANEX

(Association of Needle Exchanges)

Telephone: (03) 9417 4838

Email: info@anex.org.au

Australian Complementary Health Association

Telephone: (03) 9650 5327

Web: www.diversity.org.au

Body Art

Piercing Urge, Prahran

Telephone: (03) 9530 2244

Web: www.thepiercingurge.com.au

Chinese Herbalist

Lisa McPherson

Telephone: (03) 9687 2747 (Footscray)

Chinese Medicine Practitioner

Catherine Riva

Telephone: (03) 9844 0459 (Warrandyte)

Telephone: (03) 9596 2468 (Brighton)

Complementary Medicine

Salus Complementary Medicine Specialists

Telephone: 9500 8870 (Armadale)

Counselling

Positive Counselling HIV/Hep C Inc.

at The Bouverie Centre, Flemington

Telephone: 9376 9844

www.positivecounselling.org.au

For more Counselling information contact the Hepatitis C Council of Victoria.

Dentist

Martin Hall (Richmond)

Telephone: (03) 9420 1302

Direct Line

Drug & alcohol counselling and NSP info

Free call: 1800 888 236

Employment

Westgate Community Initiatives Group

(formerly Options Enterprises), South Yarra

Telephone: (03) 9824 2330

Equal Opportunity Commission Victoria

Telephone: (03) 9281 7111

Toll Free: 1800 134 142

Email: eoc@vicnet.net.au

Web: www.eoc.vic.gov.au

Haemophilia Foundation Victoria

Telephone: (03) 9555 7595

Hepatitis C Helpline (Counselling)

Telephone: (03) 9349 1111

Freecall: 1800 800 241

Infoshare

Self Help Addition Resource Centre,
Glenhuntly

Telephone: (03) 9572 1151

Email: info@share.org.au

Medical

Barkly Street Clinic, St Kilda

Telephone: (03) 9534 0531

Melbourne Sexual Health Centre

Telephone: (03) 9347 0244

Free call: 1800 032 017

Multilingual Hepatitis C Resources

This website has over 400 pages of hep C and HIV information in 18 languages. Go to: www.multiculturalhivhepc.net.au

Narcotics Anonymous - Victoria

Statewide service and meeting most areas.

Telephone: (03) 9525 2833

Geelong: (03) 5221 0803

Gippsland: 0405 378 513

Naturopaths

George Campbell

Telephone: (03) 9646 5455

Ondine Spitzer

Telephone: (03) 9372 0499

Gill Stannard

Telephone: (03) 9650 3419

Nawala Willumbong Co op Limited

Indigenous drug & alcohol service (St Kilda)

Telephone: (03) 9510 3233

Email: info@ngwala.org

Office of the Health Services Commissioner

Telephone: (03) 8601 5222

Complaints: (03) 8601 5200

Freecall: 1800 136 066

Royal District Nursing Service

Telephone: (03) 9536 5222

Fax: (03) 9536 5333

Email: getinfo@rdns.com.au

Victorian Aboriginal Community Controlled Health Organisation

Telephone: (03) 9419 3350

Fax: (03) 9417 3871

Victorian Aboriginal Health Service

Telephone: 03) 9419 3000

Fax: 03) 9417 3897

Victorian hepatitis C Educator

Jacqui Richmond

Telephone: 03) 9288 3586

Fax: 03) 9288 3590

Email: richmoj@svhm.org.au

VIVAIDS

Telephone: 03) 9419 3633

Fax 03) 9415 7055

Email: vivaid@vivaid.org.au

RURAL AND REGIONAL

These contacts are able to provide information about local hepatitis C related services as well as active support groups (SG).

Ballarat Community Health

Contact: Carmel

Telephone: 03) 5333 1635

Bendigo - Rural Hep C Network (CAN)

Contact: Ian Comben

Telephone: 03) 5443 2299

Email: rhcn@can.org.au

Bendigo Health Care Group

Contact: Rosie Girvan, Jane Hellstan
or Pauline Woodburn

Telephone: 03) 5454 8416

Camperdown hep C Support Group

Contact: Brian Hinchcliffe

Telephone: 03) 5593 3415

Corio Community Health

Contact: Rochelle Hamilton

Telephone: 03) 5273 2200

Drysdale Community Health

Contact: Sally McMahon

Telephone: 03) 5251 2291

Gippsland - Mobile Drug Safety

Steve Theoclitou

Mobile: 0438 128 919

Horsham - Wimmera Hep C Support Group

Contact: Jan Spencer

Telephone: 03) 5381 9378

Mildura - Sunraysia Community Health

Anne Watts

Telephone: 03) 5023 7511

Moe Community Health Centre (SG)

Contact: Catherine Ashford

Telephone: 03) 5127 5555

Portland - Glenelg Southern Grampians

Drug Treatment Service

Contact: Bev McLroy

Telephone: 03) 5521 0350

Shepparton Community Health

Contact: Merri Blair

Telephone: 03) 58 233 200

Torquay - Surf Coast Hepatitis C

Telephone: 03) 5261 3001

Wangaratta - Ovens and King CHC

Contact: Diane Hourigan

Telephone: 03) 5722 2355

Warrnambool - Western Region Alcohol and Drug Centre

Telephone: 03) 5560 3222

Wimmera (East) Region

(Birchip, Wycheproof, St Arnaud)

Naturopath/Psychologist

Phil Blackwood

Mobile telephone: 0403 625 526

Wodonga Community Health

Contact: Jenny Horan/Anita

Telephone: 02) 6022 8888

Yarrawonga Community Health

Contact: Cherie McQualter Whyte

Telephone: 03) 5744 1324

WEB FORUMS

The Australian Hepatitis Council is now running its web forum for professionals in the hepatitis C sector. Check it out at:
www.hepatitisaustralia.com/forum/publicaccess/

SUPPORT GROUP ON THE INTERNET

If you can't get to a support group, you can always go to the NSW community forum at:
<http://hepatitisc.communityzero.com/hepcnsw/>

INFORMATION & SUPPORT GROUPS

Learning about your rights, dealing with discrimination and discussing the issues that impact on you - all these things can happen in the safe environment of a Support Group.

METRO

HEPATITIS C COUNCIL OF VICTORIA:

Contact: Pier Moro 9380 4644

Brunswick Drop In & Information Sessions - open to family, partners and friends.

ALL WELCOME.

****12 Dec - Xmas get together - see page 3)**

When: Second Sunday of every month

Time: 2 - 4pm

Next: 12 Dec, not Jan, 13 Feb, 13 Mar

Venue: Hepatitis C Council Offices.

5/200 Sydney Rd, Brunswick

THE ALFRED HOSPITAL:

Contact: Sandy Breit 93276 3061

The support group now meets every second month. You must RSVP to Sandy Breit by 12 noon the day before the scheduled meeting.

****16 December - get together at Fawkner Park (opposite the Alfred). Partners & family welcome. Bring a plate.**

When: Last Thursday of the month.

Time: 1.30 to 3pm

Next: 24 March, 28 April.

Venue: Hepatitis C Clinic,

4th floor, Alfred Hospital.

Commercial Road, Prahran

ST VINCENT'S HOSPITAL:

Contact: Kate Mellor on 9288 2259

For anyone with hep C - not just those on treatment. This group runs 3 sessions a year, being 6 nights over 12 weeks. With guest speakers on particular topics with time for questions and discussions.

When: Session One: 3, 17 & 31 March,
14 & 28 April, 12 May.

Time: 5 - 6.30pm

Venue: 4th Floor, Daly Wing,

St Vincent's Hospital.

35 Victoria Parade, Fitzroy

RURAL

SALE:

Contact Lauren 5143 8800 or

Catherine 5127 5555

WARRNAMBOOL:

Contact Jeffrey on 040 124 0167

or 9486 5972

AN INVITATION TO JOIN US

FOR THE HEPATITIS C COUNCIL OF VICTORIA TO BE TRULY REPRESENTATIVE OF THE HEPATITIS C COMMUNITY, A STRONG MEMBERSHIP OF PEOPLE AFFECTED BY THE VIRUS IS ESSENTIAL.

There are 3 types of membership. Each includes all resources distributed by the Council. *By becoming a member you show your support for the peak organisation working for people with hepatitis C in Victoria.*

- 1 Individual: Entitles you to one copy of Good Liver per quarter and one vote at the AGM.
- 3 Healthcare Professional: As for individual - but includes 3 copies of Good Liver.
- 4 Organisation: As for individual - but includes 5 copies of Good Liver.

COMPLETE THE FORM BELOW AND MAIL TO THE COUNCIL.

TAX INVOICE ABN 48 656 812 701
Please ensure you retain a copy for tax purposes

Are you a new or renewing member?

Title Name _____

Occupation _____

Organisation (if applicable) _____

Mailing Address _____

Postcode _____

Local Government Area (ie Banyule, Stonnington, Casey:) _____

Telephone _____

Fax _____

Email _____

Tick one membership box. (Includes GST)

- Individuals \$0
- Professional \$33
- Organisational \$77

Donations are gratefully received by the Council \$ _____

(All donations over \$2 are tax deductible)

Total \$ _____

Are you interested in becoming a volunteer with the Council?

HAVE YOU CONSIDERED WRITING ABOUT YOUR EXPERIENCES OF LIVING WITH HEPATITIS C.

We get a lot of feedback from people saying they find it really useful to read about how someone else is dealing with hepatitis C. You may have hep C or your life may include a person with hep C. Everyone has a different story to tell and we'd love to hear yours.

It is not necessary to have your name published with your story.