

GOOD LIVER

NEWSLETTER OF THE HEPATITIS C COUNCIL OF VICTORIA



HEPATITIS C: IS AUSTRALIA HEADING IN THE RIGHT DIRECTION?

Australia has been widely acknowledged as a leader in its response to hepatitis C to date. We were the first in the world to have a National Hepatitis C Strategy, and our work in prevention, treatment, and care and support of people with hepatitis C has been widely recognised. Development of the 2nd National Hepatitis C Strategy is now nearing completion.

Despite these important efforts there are still many challenges and unanswered questions. Nearly a quarter of a million people in Australia have hepatitis C. It has been estimated that approximately 63,000 Victorians have been infected, and in 2004 there were 3034 people in Victoria newly diagnosed with hepatitis C. It has been projected that depending on the effectiveness of our response now, we will have between 321,000 and 836,000 people in Australia living with hepatitis C by the year 2020. These statistics certainly give cause for alarm.

With hepatitis C, as with any challenge, to respond effectively it is important to review where we have been, where we are up to, and where we need to go. Professor Robert Batey, Chairman of the National Hepatitis C sub-committee of MACASHH, uses his considerable expertise and experience with hepatitis C to reflect on and explore these issues in the following article.

Helen McNeill,
Executive Officer, Hepatitis C Council of Victoria

ROBERT BATEY, CHAIRMAN, NATIONAL HEPATITIS C SUBCOMMITTEE OF MACASHH

Australia has been responding to the hepatitis C epidemic since the virus was discovered in late 1989 and the Australian Government has taken a leading role in defining the Australian response to this epidemic. For much of the 1990s the government led the field worldwide in defining policy and approaches to the epidemic and this was a very exciting period. It is appropriate, at this stage of the epidemic, to review where Australia is heading, as we are now about to see the release of the 2nd National Hepatitis C Strategy.

STRUCTURAL PROGRESS

Australia has established a national body which functioned initially as Australian National Council on AIDS and Related Diseases (ANCARD), then as Australian National Council on AIDS, Hepatitis and Related Diseases (ANCAHRD), and now as the Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis (MACASHH). During the life of ANCARD the Hepatitis C Sub-Committee was formed; this body was responsible for overseeing the development of the 1st National Hepatitis C Strategy and many of the responses to this epidemic, including

the very valuable Projections Committee Reports which have defined the extent of the problem in this country. The Australian response to hepatitis C has included the involvement of the National HIV Centres for Epidemiology and Clinical Research, Social Research and Virology in hepatitis-related activities. As a result of national enthusiasm, state bodies have been established to provide advice on hepatitis C and a number of states have produced their own hepatitis C strategies, which have directed the evolution of hepatitis C services and prevention strategies in each of the Area Health Services. Hepatitis C Councils have been established and they have taken a very important role in directing how this country has responded to hepatitis C over the last ten years.

The question must be asked whether these structural responses have been appropriate. It is also important to stress that whilst many would suggest more should have been done for hepatitis C, very few diseases have specific ministerial advisory committees at a state or federal level and hepatitis has at least achieved that. Most diseases do not have national centres funded to undertake research in relation to those diseases and most diseases certainly

Continued on page 4



**HEPATITIS C COUNCIL
OF VICTORIA INC**

Suite 5, 200 Sydney Road,
Brunswick, Victoria 3056
Telephone: 03) 9380 4644
Country Callers: 1800 703 003
Facsimile: 03) 9380 4688
Email: info@hepcvic.org.au
Web: www.hepcvic.org.au

CONTACT THE COUNCIL:

Helen McNeill
Executive Officer
helen@hepcvic.org.au

Genevieve Dickson
Office Coordinator
info@hepcvic.org.au

Venetia Brissenden
Project Coordinator
Project Blood Oath
venetia@hepcvic.org.au

Linda Connor
Community Development
and Education - Rural
linda@hepcvic.org.au

Barb Healy
Community Development
and Education - Rural
barb@hepcvic.org.au

Piergiorgio Moro
Community Development
and Education - Metro
pier@hepcvic.org.au

David Samson
Community Development
and Education - Custodial Settings
davids@hepcvic.org.au

Heather Smith
Communications and Publications
heather@hepcvic.org.au

The Good Liver is produced by the
Hepatitis C Council of Victoria. The opinions
and language expressed in this newsletter
are not necessarily those of the Council.

Reader Response
Your comments or experiences in regard to
any articles in the Good Liver are welcome.
Call, write or email: heather@hepcvic.org.au

Good Liver is printed on paper made from reclaimed
industrial waste by Waterwheel Press Pty Ltd.

news:

BLUES BAD FOR HEP C

Depression can lower the effectiveness of hepatitis C treatment according to US researchers. Patients on pegylated interferon alpha-2b plus ribavirin who experienced increasing depression during treatment were significantly less likely to clear the virus after six months than patients less affected by depression. The treatment is associated with a high rate of psychiatric effects and researchers suggested patients undergo baseline mood assessments before starting treatment

*Brain Behavior and Immunity 2005
Australian Doctor, February 2005*

WEB FORUMS

A reminder for these two excellent web forums.

1. The Australian Hepatitis Council is 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/>

HEP C MASTERS DEGREE

Njernda Aboriginal Corporation Chief Executive Officer, Karlene Dwyer, has been awarded a Masters Degree in Public Health from Deakin University at Geelong. Ms Dwyer completed the course in four years, and her thesis was on *hepatitis C, its impact on individuals, their families and communities*. Ms Dwyer said the model for dealing with the effects of the virus developed in the thesis was being trialled in Echuca.

Riverine Herald, November 2004

SPUD HOPES

WASHINGTON: A hepatitis vaccine grown in genetically engineered potatoes seemed to protect most people who ate them researchers reported today. About 60% of the volunteers who ate the biggest dose of potatoes showed an immune response that should protect against infection with the hepatitis B virus.

Geelong Advertiser, February 2005

vic news:

READERS WANTED... YES YOU!

The hep C Council is revamping our information sheets. These double sided, A4 sheets are self-contained explanations on various aspects of hepatitis C, eg. testing.

We are looking for half a dozen volunteers to read them prior to their final approval. You do not need to have a medical background or specific knowledge of hepatitis C.

We'd like to know if they are easy to read/understand, are laid out in a logical way and if they cover the questions in a thorough way etc.

We would send you all the resources you'd need and a reply paid envelope. You wouldn't need to come into the Council's office, but this is an important way that you can support our work

If you are interested, please contact Pier at the Council on 9380 4644 or pier@hepcvic.org.au.

contents

- 2 NEWS/VIC COUNCIL NEWS
- 3 COMMUNIQUE EO reports back
- PREVENTION FEATURES:
- 4 Hepatitis C: Is Australia heading in the right direction?
- 5 NSPs missing from Prison Prevention Strategy
- 6 Prevention in Victorian Aboriginal communities
- 8 Peer Education Project - Wot U Can Do
- 10 Art of listening - Multicultural Communities
- 11 RESEARCH: Individualised Treatment
- 12 MY STORY: A choice in 1981 and its impact
- 14 BODY ART: Sharing skills to cut risks
- 15 DIARY DATES: roll on 2005
- 16 COUNCIL PROJECT: Project Blood Oath draws to a close
- 18 CONTACTS:
- 20 MEMBERSHIP: It's now FREE for individuals!

Welcome to the first edition of Good Liver for 2005. In this edition I'd like to let you know of some of the challenges and key activities that we have planned for this year.

A NEW STRATEGIC PLAN

After many months of hard work by the Committee of Management and staff we have almost completed a new strategic plan. We were fortunate to be guided through the process by Ann Porcino from RPR Consulting. In developing a new plan we set ourselves some strict criteria. We wanted to be absolutely honest about what our strengths and weaknesses were, to be realistic about the current environment that we work in, and to focus on what we believe will be achievable. We were also determined to keep in constant focus the issues that our members tell us are important to people with hepatitis C.

I believe we have developed a strategic plan that is bold, courageous, and achievable. This new plan sees us well positioned for the future with clear priorities and mandates for action. The new focus to our work has the staff team here at the Council very excited. I look forward to writing to you all with full details when the plan has had final approval by the Committee of Management.

FUNDING

I cannot write about challenges for 2005 without mentioning funding issues! Compared to most other statewide peak organisations dealing with similar public health issues and chronic health conditions we are terribly under-funded. We are fortunate in having a strong relationship with our funders within the Public Health Division of the Department of Human Services, however to really make a difference for people with hepatitis C we urgently need to significantly increase our income. One of my major objectives this year will be to work with the Department of Human Services to look at ways they can increase their support for our work.

I will also be extensively investigating other potential sources of income, such as philanthropic trusts.

NATIONAL HEPATITIS C AWARENESS WEEK

Many of you may be aware that this year for the first time there will be a National Hepatitis C Awareness Week. While the Australian Hepatitis Council will coordinate the Week at a National level, we still have our local organising committee who will work on Victorian activities. This year the focus will be on raising the general community's awareness of the availability of treatment for hepatitis C, and informing those that already know about treatment that the outcomes are better than they used to be. It is always startling to find how many people with hepatitis C have never been told that there is a treatment available that they may be eligible for. Recently I was informed that only 1 in 15 people with hepatitis C who are eligible for treatment are currently accessing it. While undertaking treatment for hepatitis C is still a big decision as it is lengthy and the side effects can be difficult for some people, I believe that people have a right to know about it, and decide themselves whether they wish to be assessed for it.

This year there will be a strong focus on media and also on informing general practitioners about the available treatments.

CHANGES TO THE HCCV CONSTITUTION

The Committee of Management is currently considering several possible changes to our Constitution. We would like to formally co-opt a specific position on the Committee of Management for an Indigenous community representative. The Council has been extremely fortunate to have had two representatives from Indigenous organisations on the Committee during the last two years. The change to the Constitution is an appropriate acknowledgement of our commitment to

working inclusively, but also ensures that we continue to benefit from the very specific expertise that the position brings.

The other important change being considered is that of reserving either one or two elected positions for people with hepatitis C. We are fortunate that at present we do have a hepatitis C community representative on the Committee, however again the change would be an important acknowledgement of the importance of involvement from people with hepatitis C at the highest level within this organisation. All members will be fully advised of the proposed changes prior to the Annual General Meeting.

REGULAR ACTIVITIES

Our usual education and training programs, information provision, systemic advocacy, and support groups will continue. We will continue to seek new methods of ensuring that we are aware of what is important to people with hepatitis C, and have a diverse range of ways in which people can choose to become involved in our activities if they wish. The request for readers to help with the development of our hep C information sheets on page 2 is an example of a different way that we hoping to get people living with hepatitis C involved. We recognise that many members are happy just to receive our quarterly publications, while others enjoy being more directly involved.

During this year you will hear more about all of the above. I would like to finish by thanking those members who personally made contact with us during 2004, and encouraging you to speak with any of the team here in 2005 if you have anything that you would like to tell us.

Cheers

Helen McNeill
helen@hepcvic.org.au

HEADING IN THE RIGHT DIRECTION?CONTINUED FROM FRONT PAGE

do not have consumer representation to the degree that hepatitis C has.

However, despite these significant structural activities the ANCAHRD review of the 1st National Strategy did identify failures of the previous structures including ANCARD itself, and recommendations have been made on ways to improve the structural response in the years ahead. It has been pointed out that the structure as it has evolved has failed to deliver increased treatment availability and increased research funding for hepatitis C-related activities. However, whilst criticism has been directed towards the failure of the Strategy to decrease transmission, more recent data suggest that transmission is falling and one can only hope that this continues.

STRATEGIC PROGRESS

The government has sought to establish a strategy which would optimise the Australian response to hepatitis C at a variety of levels. It has overseen the development of national guidelines on the diagnosis and treatment of hepatitis C, on testing for hepatitis C and models of care have been developed for people with hepatitis C in the general community and within the prison setting. The 1st National Strategy was a world first, and whilst it may not have achieved all that might have been hoped, it has certainly directed the national approach to this disease. The 2nd National Strategy will pick up on the successes and criticisms of that 1st Strategy.

Most criticism of the strategic approach to hepatitis C is directed towards the fact that hepatitis C has been linked to HIV funding and structures. This has been seen as unfair by the HIV lobby and inappropriate by the hepatitis C lobby, in that both bodies felt that funding was not really being directed adequately towards hepatitis C. Despite these criticisms, much has been achieved in relation to hepatitis C, which would not have been achieved if the linkage had not been made. A 'stand-alone' disease strategy these days is unlikely to

attract significant federal funding.

Strategically, Australia had led the world but currently we are lagging behind in relation to providing equitable access to optimal treatment. Strategically we need to increase efforts to reduce transmission of this disease.

EPIDEMIOLOGY AND CLINICAL PRACTICE

The Australian approach has focused on prevention from the very early days of the Strategy. Efforts have been directed towards educating the highly at-risk groups and to providing access to clean injecting equipment to reduce risk of transmission. Work was undertaken in the very early days of the epidemic to ensure the blood supply was made safe, and whilst the occasional case of hepatitis C following a medical procedure is still reported, the risk of contracting hepatitis C from the blood supply has been reduced to almost zero. Most recent data do suggest that prevention strategies are leading to a reduced risk of acquiring hepatitis C by new recruits to drug injection.

Testing for hepatitis C has been defined clearly in the recently released testing policy for hepatitis C. Australia has led the world in recommending that patients who are undergoing testing for hepatitis C should have pre- and post-test counselling to make them more aware of the significance of this disease.

The management of hepatitis C has included the counselling of patients about their disease and about the possible need for treatment, recognising that many patients do not need treatment for their disease at an early stage. Treatment of hepatitis C has been of a world class standard and the Australian Government funded hepatitis C treatments began long before many other countries in the western world. Currently, there is debate underway seeking to increase access to treatment, and that may include taking the need for a liver biopsy for at least genotype 2 and 3

patients out of the absolute requirements for this highly expensive drug protocol.

Overall the direction has been correct but more needs to be done to improve the evaluation and treatment of patients with hepatitis C in this country.

SCIENTIFIC APPROACH

Individual groups who have placed an enormous priority on this disease have led the scientific approach to hepatitis C in Australia. The fact that a number of centres are now receiving funding from the United States National Institutes of Health for hepatitis C work is a testimony to the tremendous effort that has been made by our own researchers, despite the lack of identification of hepatitis C as a priority area by our own major funding bodies (the National Health and Medical Research Council and the Australian Research Council). These bodies have funded a number of research projects, which have delivered excellent results over the last decade, but more funding should be directed towards this major epidemic in our community. Australia has been very active in undertaking clinical trials in relation to the treatment of hepatitis C; information from some of the Australian-based studies have informed the Federal Drug Administration in relation to the release of the anti-hepatitis C drugs in the USA. It would be fair to say that researchers in this country still feel under-supported by the Australian system.

ETHICAL ISSUES

There is no doubt that this disease evokes inappropriate responses in many people within the community, including those working in the health sector. Discrimination is a real issue confronted by individuals infected by hepatitis C; once again, the Australian community needs to do a lot more to reduce inappropriate responses to hepatitis C by informing the community more effectively about this disease and the risks of contracting it from casual contact.

ARE WE HEADING IN THE RIGHT DIRECTION?

The answer to this is mainly yes but at times no. Why no? We are still linking hepatitis C to HIV despite major differences between these viruses. Australia is still regulating treatment access when outcomes of treatment have improved markedly and we are still depending on Needle and Syringe Programs for prevention and not supporting such programs when they come under threat. If we do address all of these issues in the 2004-07 period, during the life of the 2nd National Strategy, we should see a fall in new infections per annum, more patients treated per annum, better informed health care workers and ultimately more funding directed towards hepatitis research.

It has been an interesting journey and hopefully, it will continue in the right direction in the next four years.

Robert Batey, Chairman, National Hepatitis C subcommittee of MACASHH

Of Substance, vol 3, no 1, 2005.

DESPITE EFFECTIVENESS, NSPS MISSING FROM PRISON PREVENTION STRATEGIES

According to Corrections Victoria's report in 2002 *"Hepatitis C Virus Among Inmates in Victorian Correctional Facilities"*, 55% of males and 67% of females in Victorian prisons are hepatitis C positive.

This compares with the incidence of hepatitis C in the general Australian community of around 1%. You don't have to be a rocket scientist to work out that prisons are a very high-risk environment for becoming infected, or re-infected with the virus. We tend to forget that almost all prisoners will eventually be released back into the community, where those who are hepatitis C positive can infect others, further fuelling this epidemic. Therefore, it would seem sensible to take whatever measures have been proven to be successful to prevent hepatitis C transmission in prisons.

Early in 2004, the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) submitted to the Commonwealth Government a report entitled *"A National Approach to Hepatitis C Care and Prevention in Australian Prisons"*. One of its recommendations was:

"Population health initiatives of proven efficacy in reducing transmission of hepatitis C and other blood borne viruses should be trialled in correctional settings. These initiatives include needle and syringe exchange programs."

So, whilst there have been some important and effective education programs in prisons around hepatitis C (in particular using trained Prison Peer Educators), what has happened to the recommendation about a needle and syringe program pilot?

Well the short answer is "nothing".

It seems that our politicians fear two things: firstly the security risks of needles in prisons and secondly, appearing to be unable to stop drugs getting into prisons.

In June 2004, the then State Corrections Minister Andre Haermeyer expressed opposition to increasing the availability of syringes in Victoria's prisons. At the same time Senator Chris Ellison, the Federal Justice Minister said he was against needle exchanges in jails. These comments were in direct response to the recommendations made by the ANCAHRD report, and other similar reports available around that time. It was later in 2004 that ANCAHRD, originally appointed by the Commonwealth Government was disbanded and replaced by the Ministerial Advisory Committee on Aids, Sexual Health and Hepatitis (MACASHH).

So it appears we are not going to sit around the table and discuss the matter. This is disappointing, considering the favourable outcomes being reported from prison needle and syringe programs in Switzerland, Germany and Spain. We could learn from these and develop a pilot program which takes into account legitimate safety concerns.

The Hepatitis C Council of Victoria's position is that whilst it is no easy task, there at least should be ongoing dialogue on the issue between governments, relevant experts and community organisations.

As Nick Crofts, now Director at the Center of Harm Reduction, says:

"We are not going to control hepatitis C in the community until we control hepatitis C in prisons".

David Samson
Community Development and Education: Custodial Settings.
davids@hepcvic.org.au

HEPATITIS C PREVENTION STRATEGIES IN VICTORIAN ABORIGINAL COMMUNITIES

Prevention is often seen as the "cure-all" to the hepatitis C epidemic. However, prevention is a complex and many pronged process that encompasses years of work and a range of broad and diverse strategies and processes.

It also assumes that people at all times want to engage in prevention processes. Does a young person engaged in using drugs really consider 'prevention' especially for a virus that may take up to 13 years to appear?

PREVENTION DOES NOT SIT BY ITSELF; IT SITS IN THE COMPLEX AND EVER CHANGING SPACE WE CALL COMMUNITY AND SOCIETY.

Prevention requires time, consistent and workable policies, an investigation of the political social context, cultural understanding and the self-reflection and development of worker practice. Prevention does not sit by itself; it sits in the complex and ever changing space we call community and society.

In the case of hepatitis C, prevention requires considerable societal change. It's a task of similar magnitude to things such as preventing poverty, war, racism or homophobia. Hepatitis C is often associated with considerable stigma and discrimination due to the transmission of hepatitis C from equipment used during injecting drugs. Currently 90% of all new transmissions in Australia are by sharing injecting equipment that has been used by someone with hepatitis C.

As a result of this, prevention strategies and the hepatitis C virus are often embroiled within the mix of societal, cultural, political and individual anxieties that surround injecting drug use.

Therefore, hepatitis C prevention strategies, processes and conversations must involve the issues of political, cultural, social and individual values and attitudes, not simply harm reduction or other prevention strategies, if they are to be successful.

Working with the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) in 2003 to address the increasing rates of hepatitis C in the Victorian Aboriginal community meant an opportunity to really investigate the practical, organisational and cultural role of prevention in regard to hepatitis C.

When the Hepatitis C Council of Victoria (HCCV) along with the Aids, Hepatitis and Sexual Health Line Inc (AHS HL) signed a Memorandum of Understanding with VACCHO, prevention of hepatitis C in Indigenous communities was high on the agenda.

Some very practical strategies were put in place as an immediate response, particularly the up-skilling of Aboriginal workers in blood borne viruses and injecting drug use. This included three 3 day training programs provided for statewide Indigenous workers about hepatitis C, HIV/AIDS and injecting drug use. These trainings worked very well and the evaluation and feedback was very positive with workers stating that the training supported them in their work practice.

However, the process of getting from the writing of the funding submission to the delivery of the training was a long one that involved self-reflection, the investigation of white privilege, politicisation and grappling with issues such as organisational change in order to make Aboriginal communities part of the core business of the Hepatitis C Council of Victoria.

The past impact of colonisation, the stolen generation and the forced dislocation of Aboriginal people from their land and culture have created a wariness of mainstream organisations, particularly health related organisations, amongst Aboriginal people.

Mainstream health organisations such as hospitals, welfare organisations and associated health agencies often provided the location in which Aboriginal people had their families taken away under racist and oppressive policies. As a consequence of this history, VACCHO wanted to work with mainstream services that had an understanding of Aboriginal Community Controlled Health.

VACCHO had worked with both AHS HL and HCCV off and on over the past seven years. Though the collaborations had been for specific training engagements and had not been ongoing, there was enough of a relationship established for VACCHO to approach these organisations. At this point prevention took on a new meaning for the two mainstream organisations.

In order to build an ongoing, quality relationship with VACCHO and the Aboriginal community vigorous self reflection and organisational change needed to occur, both here at the HCCV and at AHS HL.

This self-reflection focussed on the role that mainstream services had historically played in Aboriginal history, the privilege that belonging to the mainstream endows in our society, and the realisation that, in fact, policy, funding and awareness are biased to the advantage of mainstream services. We were forced to realise that mainstream work practice is often blind to the needs and rights of Aboriginal people and communities. It is mainstream organisations that have the responsibility to change this.

We realised that mainstream organisations have a role in providing services to all members of our society including the Aboriginal community, and, consequently spent some time thinking about what needed to change in our organisations to ensure that this happened.

So what occurred as a result of this self-reflection within the Hepatitis C Council of Victoria?

After a 2-day residential cultural awareness workshop, attended by all the facilitators of the project, certain changes were put in place.

The rural worker from the Council was allocated time and resources to work with VACCHO. This meant not only working on the project itself, but spending time with the VACCHO workers learning about Community Control and what that means for Aboriginal people. There is a real need for partnerships to be built on an equal, respectful basis. It was important for HCCV and AHSHL staff to learn about the impact of racism and structural racism on Aboriginal people.

We encountered the reality of structural racism early in the process when we realised that there are only five sexual health workers in the state of Victoria working to address the issue of the emerging hepatitis C epidemic in the Aboriginal community. Those workers also had HIV/AIDS, STI's and general sexual health within their portfolio. There were no specific hepatitis C funded workers even though the hepatitis C epidemic within Aboriginal communities is commensurate with the non Aboriginal community. We also realised that current health promotion and prevention messages produced by mainstream organisations are often culturally inappropriate and mean little to Aboriginal people.

The Committee of Management (CoM) agreed to move towards changing our Constitution to ensure representation from the Aboriginal community on the HCCV CoM. It was also decided that all CoM

members and staff would participate in cultural awareness training in early 2005.

Involvement in this project has been a steep learning curve for us as individual workers and for our organisations. However for the HCCV it was and continues to be a journey of exploration that creates greater understanding, awareness and commitment to Aboriginal people being able to utilise mainstream organisations. In the process we hope to become a mainstream organisation with workers that acknowledge, understand and provide a service that reflects the right of Aboriginal people to the same health care as the mainstream community, without the experience of racism. The HCCV also acknowledges the importance of Aboriginal Community Controlled Organisations and the sovereign right of Aboriginal people to determine and act on their own health needs.

The HCCV understands that this project is one of many as mainstream organisations change to find better and more appropriate ways of working with diverse communities.

However perhaps the lessons learnt from this one prevention project may assist in understanding some of the broader issues that mainstream organisations need to address when working with the Aboriginal community to prevent the spread of hepatitis C. Complex as that task may be.

Linda Connor
Community Development
and Education: Rural
linda@hepcvic.org.au

Get hep C free

NATIONAL HEPATITIS C AWARENESS WEEK 2005 23-27 MAY

The first National Hepatitis C Awareness Week is aimed at raising awareness of the recent significant improvements in hepatitis C pharmaceutical treatment for people with hepatitis C. The main messages for the week will be:

- Antiviral treatment for hep C has improved. 50%-80% of people on treatment (pegylated interferon and ribavirin) clear hep C
- Management of side effects has improved. 80% of people on treatment manage the side effects and complete treatment
- Access to treatment has improved. Not everyone will need treatment. Eligibility criteria (S100) determines those who need it now. Currently more than 30,000 Australians are eligible for treatment.

Deciding if treatment is right for you takes time, information and support. Your Hepatitis Council can help with this. Contact the Victorian Hepatitis C Council on 9380 4644 or 1800 300 900 (country callers).

Or visit www.hepcawareness.net.au

IF YOU OR YOUR ORGANISATION ARE INTERESTED IN BEING INVOLVED IN THE WEEK - CONTACT HEATHER AT THE VICTORIAN COUNCIL ON 03 9380 4644 OR EMAIL heather@hepcvic.org.au.

PEER EDUCATION PROJECT: HEP C WOT U CAN DO

KEITH GILBERT, PROJECT WORKER, FOOT PATROL

THIS IS A REPORT ON A 6-MONTH HEPATITIS C YOUTH PEER EDUCATION PROJECT WHICH RECENTLY TRIALLED AND EVALUATED STRATEGIES IN PEER EDUCATION WITH YOUNG IDUs IN MELBOURNE'S CBD.

The Project was run by Foot Patrol (Primary NSP mobile service, Youth Projects Inc) in partnership with the City of Melbourne, and with the involvement of VIVAIDS and the Hepatitis C Council of Victoria.

HEP C EDUCATION AND NSPS

Foot Patrol has gained a fair knowledge of the hepatitis C education needs of young IDUs in Melbourne's CBD - we now have ten years experience of providing harm minimisation services to them under our belt. Formal research projects and surveys we've conducted in recent years have indicated that peer education would be a useful strategy for educating young injectors (both HCV+ and HCV-) with the aim of reducing hepatitis C related harms.

However, while NSPs provide an ideal opportunity to reach young IDUs, our capacity to provide effective hepatitis C education is limited by a range of factors, including:

- The absence of resources (time, financial and human) to spend on researching, developing, delivering and evaluating programs.
- The client group's need for a quick, no-fuss service.
- The lack of safe spaces for IDUs.

"HEP C WOT U CAN DO" A TRIAL PEER ED PROJECT

Hep C Wot U Can Do is the name of a hepatitis C peer education pilot project funded by the City of Melbourne and conducted by Foot Patrol, between June and December 2004. The Project came about following a Foot Patrol research project "Young Injecting Drug Users and

Hepatitis C" (Thompson, M, 2003), the primary objective of which was: "to assess the level of knowledge that young IDUs have about hepatitis C". Thompson's report goes further and identifies education strategies that would be helpful for young IDUs (both HCV negative and positive). Her recommendations included:

- That the Department of Human Services provide Foot Patrol with funding to develop a peer educational project within the CBD focusing on hepatitis C prevention and safer using techniques for young people.
- That Foot Patrol targets the peer education programs to new clients and young injecting drug users.
- That all future education and information strategies be developed in consultation with young people.

In 2004, the City of Melbourne agreed to fund a part-time pilot project through Foot Patrol. Two NSP staff members - Keith Gilbert and Angela Dobson implemented the project plan, and a reference group was convened, with reps from Foot Patrol (Michelle Thompson), City of Melbourne (Kealy Smith), Hepatitis C Council of Victoria (Venetia Brissenden) and VIVAIDS (Joseph Kim).

PROJECT ACTIVITIES

In the first stage, we conducted a literature review and spoke with others who had run peer ed with IDUs in Melbourne (sadly we could only find a handful of these) in order that the Reference Group could identify and plan effective implementation and evaluation methods.

After the first meeting of the Reference Group we surveyed ten young clients of Foot Patrol to check out our preliminary ideas and to identify current priority issues in hep C - as well as to spread word of the Project. This process was key to our decision to run with these two complementary strategies -

- The "Quiz" (modelled on the SICwiz Project conducted in Wentworth, NSW)

trained up IDUs to train their friends in preparation for a quiz: in a ripple effect their friends were then invited to become trainers.

- Social marketing - a group of peers developed a range of hepatitis C education messages for print media (t-shirts and stickers).

The survey participants also provided information and perspectives invaluable to the way we worked over the next few months.

PROJECT OUTCOMES

While Hep C Wot U Can Do was a modest project - the restrictions of time and money (6 months/\$25,000) required simplicity in educational methods and content - it managed to reach around 70 young injectors in the CBD of Melbourne.

Seventeen young IDUs were directly involved in developing and delivering information and education; seven of these as trained peer educators for the Quiz, and the other ten attended a workshop to design hep C education messages for print media.

In two cycles of the Quiz, the seven peer educators reached 40 of their peers with one-one training. Unfortunately the Project ended just as it was reaching full momentum, and so it was not possible to continue the cycle of peer training-education-recruitment, despite a high interest level.

The print media education campaign will be run over Summer 04-05 (through Foot Patrol and Living Room Primary Health): the peer-developed messages will appear on stickers on 1000 fitpacks and on 120 t-shirts printed in-kind by another Youth Projects Inc program.

We were also able to provide ten young IDUs with an education session and resources on nutrition and living with hepatitis C in response to a request from the Day Program of YSAS Fitzroy.

EVALUATION

A report on Hep C Wot U Can DO has been prepared. It details our experiences, what we would repeat, and what we may do differently in future. Clearly the major learning to be taken away from this project is that: given resources and respect young IDUs respond enthusiastically, thoughtfully and responsibly to opportunities to engage with hepatitis C education. From the client survey we ran to test our preliminary ideas, to the engagement of other Foot Patrol clients as educators (in one-one settings and in developing slogans and designs), the young people contributed a great deal more than we asked of them - or indeed paid them for. They are potentially a very powerful resource.

It is not the absence of reliable peers, nor the lack of will on the part of NSPs to engage young IDUs with Hepatitis C education, that drives the dearth of peer education programs. Hep C Wot U Can Do demonstrated that peer education projects through NSPs can have dynamic results, but they need to run over years not months and be afforded the capacity to involve IDUs in all stages of the work - from the crucial, foundation stage of reflecting on and prioritising the issues, content and target groups, through delivery of education, to evaluating the impacts and outcomes.

NSPs provide the opportunity to get young IDUs acting on hep C issues for themselves and each other. What we now need to do is develop relationships and partnerships - eg with research and education bodies - with a view to securing program funding (at appropriate levels!), and ensuring appropriate professional development and planning are in place. Then you'll C Wot We Can DO.

A full evaluation appears in the project report which can be ordered by contacting Foot Patrol on 03) 96542198.

HEPATITIS C AND CONTRACEPTION: WHAT'S THE STORY?

ANNA OLSEN, NATIONAL CENTRE FOR EPIDEMIOLOGY AND POPULATION HEALTH, AUSTRALIAN NATIONAL UNIVERSITY

A project at the Australian National University is investigating an often-neglected hepatitis C health issue - sex.

A few years ago the *"Women Living with Hepatitis C Survey"* found that many women with hep C have specific needs and concerns around their sexual and reproductive health. These related to pregnancy, partners, children, sexual transmission and contraception. In particular, many of the women were not using contraception (66%). This low use of contraception was not related to socio-economic status and women who injected drugs reported equally low use of contraception as women who did not inject drugs.

Why might there be such low use of contraception? What else can women tell us about their sexual and reproductive health needs? Are women's needs being met by existing services? A new study has begun in order to find some answers.

WHY RESEARCH HEPATITIS C AND CONTRACEPTION?

You may wonder why we are researching women with hepatitis C and their contraceptive use since the virus is not considered to be a sexually transmissible infection (transmission requires blood-to-blood contact e.g. an uninfected partner having a cut, sore or opening in the skin which comes into contact with an infected partner's blood). However estimates suggest that there are at least 70,000 Australian women with hepatitis C and most of them are of childbearing age. Their sexual and reproductive health is vital especially since young women are the fastest growing population of those contracting hepatitis C (women in the 15-19 year old age group now outnumber men of the same age). Being so young and of childbearing age, most of these women will require appropriate access to sexual health care

throughout their reproductive years. This includes specific information on hepatitis C, sex and pregnancy.

Already we know that women with hepatitis C have particular sexual and reproductive health needs:

1. Undergoing combination treatment with Interferon and Ribavirin for hepatitis C requires that a patient and their partner use contraception because Ribavirin can cause birth defects both during treatment and for 6 months after treatment has finished.
2. There is some concern among doctors and women that hormonal contraception may exacerbate the effects of hepatitis C on the liver. The World Health Organisation however advises doctors that the pill can be prescribed to women with viral hepatitis as long as they are not affected by liver disease.
3. Women may also have concerns about motherhood since fatigue and nausea are among the most common symptoms of the virus and they can dramatically impact every-day life and decisions about the future - such as plans to have a family. Unintended pregnancy can also have a negative impact on women, particularly when the burden of a chronic disease is already a major disruption.

Additionally, although a low risk, the virus can be transmitted from a mother to her baby. The chance of transmission occurring is about 5%. It is not yet known why some babies born to mothers with hepatitis C contract the disease and others do not. Research has not determined whether the connection has to do with viral levels or with the birthing methods (i.e. Caesarean versus vaginal birth), or with some other aspect of pregnancy.

Continued on page 13

THE ART OF LISTENING: DEVELOPING TRUE COLLABORATION ON HEPATITIS C PREVENTION FOR MULTICULTURAL COMMUNITIES

THE MULTICULTURAL HEALTH & SUPPORT SERVICE (MHSS) WAS CONCEIVED OUT OF A NEED FOR A VICTORIAN SERVICE TO WORK WITH CULTURALLY AND LINGUISTICALLY DIVERSE COMMUNITIES (CALD) AFFECTED BY ISSUES RELATED TO HIV, HEPATITIS C AND SEXUALLY TRANSMISSIBLE INFECTIONS (STI).

The Victorian Department of Health has funded a two-year pilot which will, hopefully, become the recipient of permanent project funding post July 2005.

The service is jointly provided by Alfred Hospital and North Richmond Community Health Centre, where we are based. There have been a number of diverse and challenging issues during the past year, in terms of establishing structures which are both culturally sensitive and meet the requirements of the funding body, as well as working with the targeted groups within the so-called "four" CALD communities:

- Thai
- Vietnamese
- Horn Of Africa (Eritrea, Ethiopia, Somalia & Djibouti - however due to the present refugee influx we are also working with people from Sudan)
- Arabic-speaking (which is represented by the Arab League of Nations and comprises communities from 22 countries including Iraq, Yemen, Morocco, Lebanon and Egypt)

Working with these communities, in the spirit of a true collaboration, has entailed spending time and energy in developing meaningful relationships and listening to how communities define and prioritise their issues regarding sexual health. It has involved responding appropriately to community concerns and re-assessing policies and procedures, which are often not culturally appropriate.

Pivotal to the success of MHSS is the role of our four bilingual/bicultural co-workers, who provide the bridging support between the communities, the service, and mainstream service providers. Employing bilingual/bicultural staff has been a challenge and has involved listening to the communities in terms of what skills they regard as essential in a co-worker, and how to balance this with what we consider essential.

In addition to the importance of the co-workers in determining whether this service will be a success or a resounding failure, is not just "talking-the-talk" but "walking-the-walk" in terms of listening to communities, responding to communities and ensuring the communities have a real sense of ownership of this service and its future directions. This means that social capital and mutual respect are integral and we have a diverse steering committee whose representation works very hard to reflect this. Which often means we all have to listen more and forget any notion of being "experts" in our area of passion!

We are currently delivering community health education sessions in the communities and often share the cultural beliefs amongst ourselves! Even being able to do this in a light-hearted way demonstrates that we are developing a relationship of trust as a team. We have heard that chilli gives you hep C, eating caraway seeds cures HIV and that as long as you don't go any closer than 50 metres to a person with hep C you will be OK!

We have information lines in all community languages, regular spots on SBS and community radio and have established a clinical support service where we provide written and verbal information in community languages. An important component of clinical support is assisting in linking and supporting clients into mainstream health services and we have close relationships with both Melbourne public hospitals and

specific health providers. We also intend to offer mainstream service providers training in working with CALD communities in 2005.

The Multicultural Health & Support Service values client and community feedback and all advice and suggestions are given serious consideration. Developing as a meaningful service involves being able to monitor and evaluate our service on a continual basis to ensure we are delivering the absolute best to the communities we are working with.

This year we intend to focus strongly on health promotion and prevention, and working in partnerships with communities and a wide range of organisations is the most effective way of communicating these messages. Working with the Hepatitis C Council of Victoria is an excellent example of effective community collaboration and we look forward to meeting communities and their representatives during the National Hepatitis C Awareness Week during May 2005.

We can be contacted either through:

- English speaking direct line: 9420 1339
- Vietnamese direct line: 9420 1383
- Thai direct line: 9420 1375
- Horn of Africa direct line: 9420 1379
- Arabic speaking direct line: 9420 1329

All information is confidential and all services are free. We are happy to provide written information in community languages, or discuss concerns either over the telephone or face-to-face. We are very happy to welcome people to our office, which is located at Richmond Community Health Centre in Richmond.

Kate Bean
Service Manager
Multicultural Health & Support Service
Telephone: 03) 9420 1339
Email: kateb@nrhc.com.au

LANDMARK HEPATITIS C STUDY OF INDIVIDUALISED TREATMENT TO ADDRESS GROWING EPIDEMIC (FROM MEDIA RELEASE)

A landmark hepatitis C study, the largest of its type ever conducted in Australia and the Asia Pacific region, will investigate more effective methods of treating this debilitating disease by tailoring anti-viral therapy to the individual characteristics of patients.

The Genotype 3 Extended Treatment for Hepatitis C (GET-C) study is aiming to optimise cure rates* by individualising the dosage and duration of anti-viral therapy according to the particular strain (or genotype), viral load and weight of the patient.

Recruitment for the study has been announced in 33 centres across Australia, with investigators aiming to complete 624 patients on a treatment program. This research is made possible by the support of Schering-Plough, who are providing assistance worth over \$6 million.

The GET-C study will compare the responses of patients with a high viral load to weight-based doses of pegylated interferon combination therapy for treatment periods of 24 and 48 weeks.¹ Patients with genotype 3 typically have cure rates* of approximately 80% within 24 weeks of treatment.²

Australia is in a unique global position to lead cutting-edge research in the study of hepatitis C genotypes. Approximately one third of all Australian patients are infected with the genotype 3 strain of hepatitis C – a significantly higher proportion than in any other developed country.³

Hepatitis C is the most frequently notified communicable disease in Australia, with an estimated 242,000 Australians having been exposed to the virus. Around 143,000 of these cases are estimated to have progressed to chronic infection, placing a huge burden on the public health system.⁴

Melbourne-based hepatologist and chief investigator on the GET-C study, Dr Stephen Pianko, said that personalised methods of treatment may result in better outcomes for patients.

"Clinical evidence points to hepatitis C patients' genotype, viral load and weight all playing important roles in influencing their response to combination therapy," he said.

"Our study will explore whether individually tailoring the dosage and duration of combination therapy to these characteristics amongst patient populations can optimise cure rates*."

"Hepatitis C is now the leading cause of liver transplantation in Australia. By more effectively treating the disease early, we can prevent patients needing such costly and invasive treatment later," Dr Pianko said.

FURTHER INFORMATION ABOUT THE GET-C CLINICAL TRIAL FOR HEALTHCARE PROFESSIONALS AND INTERESTED MEMBERS OF THE PUBLIC IS AVAILABLE BY CALLING 1800 023 246.

PBS listed under Section 100 for the treatment of chronic hepatitis C in patients who have received no prior interferon therapy. Patients must be 18 years of age or older and must have compensated liver disease. Please refer to the Pharmaceutical Benefits Schedule for further information.

REFERENCES

* As defined by sustained viral response (SVR), the standard measure of clearance of the hepatitis C virus. This is defined as being undetectable plasma HCV-RNA levels after therapy and for six months afterwards.

1 Phase IV study of tailored therapy with Peg Interferon alpha 2b and Ribavirin for patients with Genotype 3 HCV infection.

2 Zeuzem S et al. Peginterferon alfa-2b plus ribavirin for treatment of chronic hepatitis C in previously untreated patients infected with HCV genotypes 2 or 3. *J Hepatology* 2004;40(6):993-999.

3 McCaw R et al. Hepatitis C virus genotype in Australia. *J Viral Hepatitis* 1994;4:351-357.

4 National Centre in HIV Epidemiology and Clinical Research. *HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia: Annual Surveillance Report 2004*. University of NSW. 2004:13.



Evaluation of the National Hepatitis C Resource Manual. Have Your Say

The Department of Health and Ageing has commissioned independent social researchers Urbis Keys Young to evaluate the National Hepatitis C Resource Manual. The Manual is available in hard copy and on-line at: http://www.health.gov.au/internet/wcms/publishing.nsf/Content/health-pubhlth-strateg-hiv_hepc-hepc-manual.htm

As part of the evaluation we're seeking the views of agencies, people with hepatitis C and their carers, and others who have used or are familiar with the Manual. We're conducting an online survey to ascertain users' views on the content, presentation, distribution and usefulness of the Manual, which will be used to inform the production of a future edition.

The survey will be available at www.urbisjhd.com/hepcmanual.htm between 11 March - 1 April. If you would like to receive an email with a link to the survey when it's available, or if you have any questions about the survey, please send an email to: hepcmanual@urbisjhd.com."

decisions

my story

I contracted hepatitis C as a teenager when I made the simple decision to inject amphetamines. I thought it might make me feel better. It was November 1981, the start of the 'me' decade. Bob Hawke got on the wagon and cried on television as he spoke about his drug-addicted daughter. The Reagans told Americans to 'just say no' to drugs. I sat in a bungalow in an affluent bayside suburb of Melbourne and said 'yes'. Should I have just said no? Was there any real choice?

By late high school, without noticing, I had already been shaped by the billions of indistinct moments that make up a childhood. I was much like a block of raw material that is slowly and meticulously moulded by the sculptor into something defined and inescapable. Yet I was stranger to myself - an awkward girl who flinched and ducked around the painful present.

My first home was the apartment above my parents' chemist shop. My mother's father died of TB when she was four. My mother, her brother and my grandmother boarded with various relatives who used them an example of their charity. She was a precocious child and funded her education through a variety of scholarships. Everyone said she had a bright future. As a new parent she fed dinner to everyone except herself. She somehow missed the movement that enlarged women's lives and instead strove every day to fit into the two-dimensional role of a magazine wife.

My father had an expensive boarding school education that eventually led to two failed pharmacy businesses. He didn't like children but reluctantly agreed to father two more. When he wasn't working in the shop, he mowed the lawns and dealt out pocket money and made an art of finding fault with his children.

I was a difficult child and was often accused of being 'full of the joy of life'. I walked too early, talked too much, asked too many questions and demanded too much attention. I was swatted away like a fly to make way for the needs of the customers, my younger brothers and the four loads of dirty nappies each day that had to be put through the manual wringer before they were hung on the line.

I developed asthma as I was forced out of my babyhood through necessity and without remorse to make way for the first son. When I was sick, I was breathless and wordless - suffocated into submission. My mother would attend to me with all the skill and care of a nurse who'd won statewide nursing awards. She was patient, loving and beatific. She slept next to my bed in a chair and woke me regularly to dispense in precise measurements the mixtures made up by my father from the brown bottles in the back of the chemist shop.

When I could breathe a little easier, my mother would go back to her crumbling domestic life with some sense of fulfilment and my father would stand at the end of my bed smoking a cigarette and tell me that asthma was all-in-the-head. I was confused and unnerved by an accusation that I didn't understand.

As I got older, my father left home and the seeds of mental illness found fertile ground in my mother's mind. I gained the independence of a child of an overworked single parent. By the age of six I had responsibility for my medication. Sometimes, I doubled dosed. Sometimes I swallowed pills that should have been inhaled. Most of the time I put them down the bathroom sink so no one would find out I had been too lazy to take them. I was a regular patient at the Clinic. The doctors were caring and friendly and always gave me a prescription. When I was really ill they would tape an injection of adrenalin in my arm and slowly push in the contents over ten minutes.

Eventually they sent me to a specialist who tested me for allergies. He put lines of liquid drops on my forearm and scratched the skin through each drop. There was something so reassuring about lumps on the arm. They weren't all-in-the-head. The

family doctor gave me twice-weekly injections to desensitise me. I never did understand the nervous giggling of my classmates at immunization day at school.

In my first year of high school we had a progressive English teacher. On a Friday afternoons he would put books along the blackboard ledge for us to read. I was 12 years old when I read Valley of the Dolls and Go Ask Alice. I was both intrigued and repelled by these self-destructive women who used prescription and illegal drugs. They seemed both tragic and glamorous.

My academic grades appeared to be erratic but corresponded directly with the quality of my relationship with the teacher. Some years I got an A for French, others an E. I was bored and withdrawn and my home life became increasingly chaotic. I started missing school. First I would watch midday musicals. Then I started spending time with other wounded teenagers. We started by experimenting with alcohol. I can still remember my first drink - a vodka and orange UDL - and the lovely cotton wool feeling. I was fourteen.

It wasn't long before I tried my marijuana. I listened to Jimmy Hendrix, Janis Joplin and Jim Morrison while everyone else was listening to Adam and the Ants, Flock of Seagulls and Duran Duran. I hung out in a dilapidated bungalow, which became a clubhouse for the neglected and confused. In this oasis from school and home, I found a place where I was validated and admired by my peers. I started taking amphetamines at sixteen. Without them I was sluggish and grim. With them I was euphoric and energetic.

After 18 months, I woke up one morning and stopped taking drugs. Something had clicked and I understood in some fundamental way that drugs were a dead-end for me. It took a year to recover from the malnutrition. It took even longer to recover from the less tangible damage of an unstable childhood.

I enrolled in a secretarial course and got my first suit and my first job. In the mid-80s I backpacked through Europe and returned to study my VCE and a university degree. I received a Premier's VCE award and won a scholarship to study in the USA.

It was at this time that I was diagnosed

with hepatitis C. The diagnosis did not impact on me at the time. I was dealing with something much more frightening - the gruelling fight against constant despair and consuming neediness. My only respite was alcohol and then food. Eventually, as I neared mental collapse from the strain of holding the threads of my life together, I was referred to a psychotherapist who over a period of 8 years quietly and assuredly nourished me to mental health. In my experience, drugs are often blamed for the crumbled life of an addict. In my case the drugs were just another prescription for an ailment that I'd had my whole life.

As I slowly moved from surviving to living and re-engaged with the world, I made friends with a group of amazing women, developed a passion for the arts and learnt how to nourish my body with food, rest and exercise. I also started bushwalking. One month before my psychotherapist died in a car accident I met my husband on a bushwalk. While I am a lesser person for losing her, her legacy is a wonderful husband who makes feel safe and secure and loved every day. We recently had a cheeky and active baby boy who doesn't like sleeping but who has the easy laugh of a child who is well loved.

And what of my hepatitis C? It is like a backpack that I carry with me. Sometimes it feels almost weightless and I forget it is there. Sometimes it is weighed down with serious consequences that directly impact on decisions I make about my future and the future of my family. The virus has at times made very positive contributions to my life. At other times, it has caused me great concern. It also shapes my identity. I am sometimes a person who is well or sick. Other times I am a person who has had troubled times or who has overcome significant hurdles. All of these personal issues can fluctuate as much as my ALTs.

I don't know what the future holds for my family and me. I can only do my best to live happily and take care of my health. At times I wish I could return to 1981 and sit with that vulnerable young girl. What could I teach her? What would I learn from her? I'll never know. Perhaps all I can do is accept her as a part of me.

Anon

research:

HEPATITIS C AND CONTRACEPTION: FROM PAGE 9

In order to address these and surrounding issues, researchers will interview women about their experiences with the virus and how this may impact their sexual and reproductive health, especially their use of contraception. Participants' stories will help researchers to paint a picture of what specific contraceptive and reproductive health advice is needed for Australian women with hepatitis C. Service providers and policy-makers will be involved and recommendations on how to improve access to sexual healthcare will be developed.

WHAT ABOUT MEN, SEX AND HEP C?

Some male partners of women with hepatitis C will also be interviewed in this study because it is important to understand how couples use contraception, not just women. Little is known about the impact of hep C on relationships or on sex and researchers would also like to know what men think about contraception and reproduction.

How can men take part in the study? Through their female partners. Women who are interviewed will be asked if their male partners want to participate as well.

WOMEN, WOULD YOU LIKE TO HELP?

If you are a woman living with hep C in the ACT or Melbourne and are interested in helping researchers to improve the health of women with hep C please contact:

Melbourne: Toll free 1800 227 440
(Anna Olsen)

ACT: Toll free 1800 227 514
(Cathy Banwell and Phyll Dance)

Everyone who takes part will be offered \$20 for their initial contact with the study.

All enquires and participation remain confidential.

DID YOU KNOW?

Australian Women and Hep C study main findings.

Who?

- 462 HCV+ women in Victoria and the ACT
- Mean age 35 years old

Women and hep C testing:

- Seventeen percent of women received pre-test counselling before being tested for hep C
- Fifty percent of women received post-test information or counselling after being tested for hep C

Women and hep C healthcare:

- After being diagnosed 55% of women said that they would have liked to have received more information on hep C
- Since being diagnosed 52% of women had been referred to a liver specialist
- Current and past IDUs were least likely to have been referred to a liver specialist
- Most women with hep C have not received clinical treatment (only 17% have ever begun interferon-based combination or monotherapy)
- Most women with hep C do not manage their illness through specialist care
- Approximately one-third of women had tried alternative therapies
- Forty-eight percent of women reported experiencing less favourable treatment by a health professional because of their hep C

Women and hep C symptoms:

- Fifty-eight percent of women report experiencing symptoms related to their hep C
- The most common symptoms reported were tiredness, nausea and psychological/emotional problems

Woman, hep C and sexual health:

- Thirty-four percent of women were using contraception
- One-third of women became pregnant after being diagnosed with hep C
- A small number of women had been advised not to go ahead with a pregnancy because of their hep C status
- Eighty percent of women were sexually active and 39% of these women reported that hep C was a concern in their sexual relationships

BODY ART: SHARING SKILLS & EXPERIENCE TO CUT THE RISKS

The Piercing Urge was established in Melbourne, in 1991 to meet the small but growing need for safe installation of body jewellery. The gay and lesbian communities along with those living as part of the alternative culture scene generated much of this initial need. Our aim was to provide an environment where people could go to find out more about this emerging trend and explore their own desires in the world of body piercing.

During the early 90's much of the piercing being performed at The Piercing Urge was closely linked to the sexual aspects of body piercing. It was part of the gay and lesbian, S&M, gothic and leather lifestyles, as well as older straight couples looking to add some extra fun to their sex life. During this time we also saw piercing become part of commitment ceremonies for couples (far more useful than a ring on a finger) and a way of signifying rites of passage, marking beginning or completed stages of life.

As piercing became more visible, the mainstream community began their exploration and during the mid to late 90's we experienced an explosion in the piercing industry in Australia. It was at this time that body adornment, in the form of navel piercing, was embraced by many and so started the popularity for body piercing that continues today in the more visible types of piercings such as nostril, eyebrow and labret.

The Piercing Urge has watched and participated in the development of our industry in Australia, however it is now from a position of both happiness and horror that we contemplate the future. The rapid growth of this industry has taken many by surprise and it has been subject to many unethical practices over recent years. The future stability of the body art industry relies on practitioners doing the right thing and sharing factual information with both the general public and the government. To that end, we decided to formally share our knowledge and skills so that we can all work towards securing the future for body piercing in Australia.

COURSE MOTIVATION

There are many reasons for deciding to start the educational branch of The Piercing Urge. For many years we have resisted the idea primarily because we felt it was impossible to teach others what they needed to know in a day or two. The best way to learn the art of body piercing has always been under the guidance of an experienced piercer in a busy studio where you are taught all aspects of piercing in a supportive and safe environment. However, over recent years the demand for people wanting to learn how to pierce has far exceeded the number of positions available in good studios. Consequently the need for a course type environment has become necessary and there are different courses



now available. The Level 1 Piercing Urge training course runs for 8 days and teaches all the essentials required to pierce in a safe, ethical manner. The Piercing Urge has always operated with the highest standards and we now feel it is important to share those standards with others so that they may:

- Have a benchmark standard.
- Know what to look for when choosing a place to work.
- Know how to raise the standard in their existing place of work.
- Know how to set up a best practice studio.
- Know that health department guidelines are a minimum standard.
- Have the most current information available concerning jewellery, equipment and techniques.
- Develop a network of like minded people.
- Contribute to raising the standard of body piercing available in Australia.

One of our greatest concerns has been the lack of training courses focusing on sterilisation and cross-contamination prevention. These are two of the most significant issues within the piercing environment concerning public health. Correct handling of bodily fluids is essential to prevent viruses such as those in the hepatitis family being contracted as a result of receiving a body piercing. Having





a body piercing should be fun and not result in the client getting anything more than what they paid for.

In 2004 the Department of Human Services in conjunction with the skin penetration industry, developed a new set of standards that will be used by Environmental Health Officers to inspect skin penetration premises such as body piercing studios and tattoo studios. These standards should result in an increased awareness amongst studio operators as to what is a safe standard to operate within, particularly concerning sterilisation, record keeping and cross contamination. When implemented, we should see a significant reduction in the spread of disease within some skin penetration businesses.

So, with tools such as the updated Skin Penetration Guidelines, the Inspection Audit Tool for EHO's and Level 1 Piercing Urge Training Course, the industry as a whole should see an increase in the number of premises that are operating in a safe, publicly responsible manner. Body piercing may then be enjoyed safely for many years to come.

Piercing Urge
03) 9530 2244

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

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.

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 **Glenn** on **0437 680 748** or email: breakingthechains@hotmail.com

diary:

**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 - 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

**24 - 27 AUGUST 2005
17TH ANNUAL ASHM CONFERENCE**

To be held in Hobart, Tasmania and will include sessions on hepatitis. Running back-to-back with **2005 Australasian Sexual Health Conference**. More details: www.ashm.org.au/conference2005

**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

HEPCHAT BACK FROM HOLIDAYS

HepChat is back on air after the break - every Thursday from 10.30 to 11am.



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**

PROJECT BLOOD OATH WINDS UP!

Good Liver readers may remember from the 2004 Spring Issue that the Hepatitis C Council of Victoria has been piloting a project aimed at preventing hepatitis C transmissions among homeless young people. Well, how time flies! Project Blood Oath has been running now for almost nine months and is due to finish up in mid March.

This Project was always going to be a demanding one. Young people are notoriously hard to reach with prevention messages and homeless young people even more so. To develop, implement and evaluate something meaningful within the tight 10 month time frame only added to the challenge.

It was a challenge however, very much welcomed by the Council, as it represented the chance to engage with the issues facing young people around hepatitis C transmission. While the Council has done a significant amount of work with schools (the Body Art Kit for school nurses, for example), there has been a not altogether unwarranted perception in some quarters that we have not catered well to young people at risk of hepatitis C and that we are more comfortable working with or for an older age group. It is certainly true that Project Blood Oath has provided an



Welcome aboard! Wayne Neilson and Bridget McAloon from Open Family

opportunity to develop new and mutually beneficial relationships with organisations such as Open Family, Melbourne Citymission, and YSAS, to name a few. It is our hope that these relationships will be called upon to inform future prevention programs and that our experience in piloting Project Blood Oath will stand us in good stead when seeking to be inclusive of young people in our overall strategic directions in the future.

There has been a gap and we have been conscious of it. Of course we are a small organisation facing an epidemic and it is impossible to ensure coverage of every sector of the community. However to reach young people, just prior to or just commencing injecting drug use and to actually change their behaviours is to have a significant impact on transmission rates.

To assist in developing and implementing the project, the Council engaged the skills and experience of the project partners Open Family Australia, Melbourne Citymission and the research team from Project i at the University of Melbourne. Other organisations, such as YSAS, VIVAIDS, and the Salvation Army helped to make up a lively and useful Steering Committee.

The project took two different approaches. The first aimed to reach young people on the streets via an outreach bus offering food and drink, needles and syringes, condoms, and information. An Open Family outreach youth worker accompanied the bus on its outings and was available to assist young people who wished to access hepatitis C testing or other services. A youth friendly booklet was also handed out, containing information on where to get cleans fits and further information on hepatitis C.

We initially had trouble determining the best locations and times to operate the bus in order to 'capture' young people who fitted the targeted profile (12-19 years old and experiencing homelessness). Over the last month or so, we have been parking next to the flats at the top end of Brunswick Street and in the shopping precinct in Footscray. Both of these sites have afforded contact with a steady stream of young people experiencing difficulties with housing and identifying as current or prior drug users. However, anecdotally what we have experienced so far is good contact with people in the 19-26 yr age group who have several years experience with injecting drug use. Either we are not in the right locations or an outreach bus is not



Blood Oath Project Coordinator, Venetia Brissenden at the wheel.

the best method. Whatever the reason, younger homeless people not yet injecting drugs are proving difficult to reach.

It will be very interesting to see the results of the more than 100 surveys completed by people accessing the bus, once the evaluation of the project is finished and the data has been sorted. In the meantime, I have taken heart from the many useful conversations I have had on the bus with young drug users about available treatment for hepatitis C, where to get tested or access clean gear, and how to inject more safely. It has been almost shocking for us as workers to notice just how many of the young people accessing the bus have identified themselves as hepatitis C positive, while at the same time being remarkably uneducated about the treatments available for hepatitis C and the particulars of injecting safely and avoiding transmission. This has shown us that there is a clear need for services for this age group which, although not the original target group, the bus has been able to meet to a certain extent.

The other component of the Project involved delivering hepatitis C training to workers from a number of agencies working specifically with young people with the expectation that these workers would then train their colleagues, who would apply this knowledge in their work with young people. A full day of training, a manual and follow up support was offered to workers from 6 different agencies. Several of these workers have already run training for their colleagues and it will be interesting to see the results from the surveys completed by staff at the various locations. Initial feedback from the 'train the trainer' participants has been positive, but it remains to be seen whether the training has impacted on the interactions of the workers with the young people in their care.

The education component of Project Blood Oath reflects the need for young people to receive education and information on hepatitis C from a person they know and trust. It is service workers, engaging in the day to day contact with young people, listening to their experiences, answering their questions and providing much needed services who are uniquely placed to provide crucial information on hepatitis C and strategies to minimise risks. It is therefore important that service workers feel comfortable with their level of knowledge about hepatitis C, (for example, how it is transmitted, where young people can get tested, what the different diagnostic tests mean and how hepatitis C can be prevented) as well as familiar with the contexts in which young people may be at risk of acquiring the virus.

It is my belief that an answer to the particular difficulties involved in engaging with young people around risky behaviours in general (hepatitis C is, after all, only one of the many harms associated with drug use) has probably not been identified or addressed by this Project. This would, after all, be a big ask of a 10 month intervention. What realistically we have hoped to achieve is a greater confidence among workers of their knowledge around hepatitis C when they go about their

business of interacting, engaging and influencing the young people they work with. We have at the very least made an addition to the current knowledge about what interventions do and do not work in minimising hepatitis C transmission among this vulnerable population.

We hope ultimately that Project Blood Oath will help us to develop a workforce within the homeless youth sector that has the capacity and knowledge to deliver targeted hepatitis C education to the young people engaged with their services. We anticipate that one of the outcomes of this process will be a markedly increased focus on hepatitis C within the services, and the development of a hepatitis C specific network amongst the involved services. If all of this occurs, the Council, our partners and the Blood Oath Steering Committee can consider our job well done.

'Venetia Brissenden
Project Coordinator - Project Blood Oath
venetia@hepcvic.org.au

**}clean fit
every}hit**

LIVER CLINICS

Albury/Wodonga

Telephone: 02 6024 5255

Alfred Hospital

Telephone: 9276 2223

Austin/Repatriation Medical Centre

Telephone: 9496 2787

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

Jane Daley

Telephone: (03) 9500 8870

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

Solicitor

Mary Simpson

Slater & Gordon

Telephone: (03) 9600 0290

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 McMahan
Telephone: 03) 5251 2291

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 McIlroy
Telephone: 03) 5521 0350

Shepparton Community Health

Contact: Merri Blair
Telephone: 03) 5823 3200

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.

When: Second Sunday of every month

Time: 2 - 4pm

Next: 13 Mar, 10 April, 8 May, 12 June

Venue: Hepatitis C Council Offices.

5/200 Sydney Rd, Brunswick

THE ALFRED HOSPITAL:

Contact: Sandy Breit 9276 3061

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

When: Last Thursday of the month.

Time: 1.30 to 3pm

Next: 24 March, 26 May.

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 0972 or
Catherine 5127 5555

WARRNAMBOOL:

Contact Jeffrey on 0401 240 167
or 9486 5972 or Glenn on 0437 680 748

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.