

GOOD LIVER

NEWSLETTER OF THE HEPATITIS C COUNCIL OF VICTORIA



VICTORIAN HEPATITIS C STRATEGY FINALLY SEES LIGHT OF DAY

“WE ARE ALARMED AT THE INCREASE IN HEPATITIS C INFECTIONS OVER RECENT YEARS, FROM 3,550 IN 1994 TO MORE THAN 5,000 IN EACH OF 2000 AND 2001 AND THIS HIGH RATE LOOKS SET TO CONTINUE, WITH 2,310 NOTIFICATIONS IN THE FIRST SIX MONTHS OF THIS YEAR”

So began the Minister of Health and Deputy Premier, Mr John Thwaites, as he launched the long awaited Victorian Hepatitis C strategy. More than 200 people attended the launch on Monday 28 October which was held in conjunction with the official opening of the new premises of the Burnet Institute of Medical Research and Public Health.

Professor Steve Wesselingh, Director of the Burnet Institute and Convenor of the Victorian Hepatitis C Strategy Committee opened the proceedings by welcoming guests and introducing the Minister of Health and Deputy Premier, Mr. John Thwaites.

In his speech, Mr Thwaites stated that the Bracks Government aimed to combat the unacceptably high infection rate with a commitment of \$546,000 for four initiatives to fight hepatitis C. These are:



Carlo Campora, Manager, Hepatitis C Council of Victoria with Minister of Health and Deputy Premier, Mr John Thwaites at the Launch.

- \$241,000 for the education and training of the needle and syringe workforce;
- \$150,000 to develop a Victorian Multi-cultural HIV/AIDS and hepatitis C Service;
- \$100,000 to the Hepatitis C Council of Victoria for state wide Hepatitis C workforce development for health educators; and
- \$55,000 to the Access Information Centre at the Alfred Hospital to develop Internet based education about Hepatitis C for secondary school students.

He also said that the government had provided \$7.5 million to assist with building the new Burnet Institute facilities, which included world-class laboratories. The institute has been successful in

attracting Professor Eric Gowans from Brisbane, to continue his internationally recognised work on developing a vaccine against hepatitis C.

The next speaker was Professor Peter Doherty, a Nobel Prize recipient for his work in immunology. He spoke enthusiastically about the importance of the four initiatives to control the spread of hepatitis C. He stated that organisations like the Burnet Institute play a crucial role in these initiatives as they are able to synthesise both the scientific and social aspects of the virus. These attitudes are refreshing, he remarked, compared to countries like the United States, where a more conservative social climate has hindered the effective fight to control the spread of diseases like hepatitis C.

The final speaker, Ms Moira Burke, spoke powerfully about her own experiences of living with hepatitis C and the importance of keeping the social aspect of hepatitis C central to any strategy to reduce the impact of the virus. Ms Burke went on to explain:

‘Whilst I agree with the sentiment that it shouldn't matter how you contracted the virus, the reality is that it does matter.

It matters because the majority of

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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: hepcvic@vicnet.net.au
Web: www.hepcvic.org.au

CONTACT THE COUNCIL:

Carlo Campora

Manager
ccarlo@vicnet.net.au

Venetia Brissenden

Community Development
and Education - Custodial Settings
venetiab@vicnet.net.au

Linda Connor

Community Development
and Education - Rural
lindac@pipeline.com.au

Jenny Dale

Administration/Resources
hepcvic@vicnet.net.au

Barb Healy

Community Development
and Education - Rural
barbdv@netc.net.au

Jen Johnson

Project Officer - Body Art
jenj@vicnet.net.au

Piergiorgio Moro

Community Development
and Education - Metro
pmoro@vicnet.net.au

Heather Smith

Communications and Publications
heathers@vicnet.net.au

The Good Liver

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 very welcome. Call, write or email: heathers@vicnet.net.au

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VICTORIAN HEPATITIS C STRATEGY FINALLY SEES LIGHT OF DAY



ABOVE: Ms Moira Burke speaks at the Launch

FROM THE FRONT PAGE

infections occur through sharing injecting drug equipment. It matters because of the stigma imposed on people who inject drugs, and the discrimination that often follows. Addressing hepatitis C should be a straight forward health issue, but it's not.

The hard social issues around injecting drug use need to be tackled; not ignored, or overlooked, or swept aside, or buried under a deluge of more pressing issues. Effective social strategies must be implemented; strategies that will help people avoid contracting the virus by empowering them and normalising their behaviour.

Without addressing the social issues that underlie the disease, the spread of the virus is unlikely to ever come under control.'

Piergiorgio Moro

Community Development & Education

**COPIES OF THE VICTORIAN
HEPATITIS C STRATEGY CAN BE
OBTAINED BY CONTACTING THE
COUNCIL.**

A SNEAK PREVIEW

VICTORIAN HEPATITIS C STRATEGY 2002 - 2004

The first Victorian Hepatitis C Strategy was developed and implemented in 1996. This second Strategy builds on the first and identifies new initiatives that will help strengthen Victoria's responses to the current and emerging challenges of the hepatitis C epidemic.

It is intended to provide direction for necessary areas of action around prevention, education, treatment, care and support, to meet the needs of people who are affected by hepatitis C. The success of the strategy relies on the effective participation and cooperation between different groups within the hepatitis C sector.

Very briefly, the key priorities and their areas for action are:

1. Prevention and control of hepatitis C transmission

- Implementing the National Hepatitis C Testing Policy
- Developing NSPs
- Enhancing drug treatment services
- Addressing needs in correctional settings
- Improving skin penetration practices
- Reviewing police activity in street based drug markets
- Developing blood borne virus education in schools

- Implementing a general population awareness campaign
- Improving test discussion and pre and post test counselling protocols
- Evaluating educational processes

2. Preventing discrimination and reducing stigma and isolation

- Improving access to services
- Enabling the workforce
- Reducing discrimination in health care services
- Legislation

3. Health maintenance, care and support for people affected by hepatitis C

- Incorporating best available evidence
- Strengthening the work of natural and complimentary therapists
- Building on peer education activities
- Strengthening services for people who inject drugs
- Developing services for regional and rural areas
- Improving access to services in correctional settings
- Vaccinations

4. Research and Surveillance

- Developing research activities
- Implementing an active surveillance system
- Identifying incident hepatitis C infections
- Integrating surveillance, research and intervention activities
- Social research activities

5. Pharmaceutical Treatments

- Improving access for people who inject drugs
- Servicing the needs of people from culturally and linguistically diverse backgrounds
- Improving access for people in correctional settings
- Addressing the needs of people in rural and regional areas
- Providing care and support
- Supporting services for people with HIV co-infection
- Developing shared care
- Developing the role of Nurse practitioners
- Ongoing Assistance
- Reviewing Guidelines
- Government Review

news

COUNCIL WEB SITE BACK ON LINE

At last! After a lot of hard work, the Council's exile from the web is over.

www.hepcvic.org.au

A heart felt thanks goes to Min and Vytas from Imaging Services Group for the design and technical know how, to Venetia for the rewriting and all the others who had input. **We also welcome your comments**, so don't hesitate to contact **Heather** on 9380 4644 or heathers@vicnet.net.au

ADVANCED NOTICE FOR HECLE MEETINGS

HECLE is a forum for discussion, peer support and information for health educators. The dates for 2003 are February 26, July 30 and November 26. For more information contact Barb at the Council or email barbdv@netc.net.au.

DONATIONS TO THE COUNCIL ARE NOW TAX DEDUCTIBLE

For a community organisation such as the Hepatitis C Council of Victoria, donations are the 'bit extra' that helps our activities flourish.

GL REVISITS SPRING ISSUE

It was reported in the GL Spring issue that Robert Doyle, leader for the opposition had publicly supported the Bracks Government on the issue of establishing 5 medically supervised injecting rooms. The article was taken from an email list, but it has since come to GLs attention from other sources that the facts may have been wrongly reported. GL is still investigating, but in the meantime the release of the Liberal Party Drug Policy for the recent State Election makes interesting reading.

We quote: "The first step is to provide real leadership and moral clarity...the Liberal Party will oppose any moves toward heroin injecting rooms, and will take a strict zero tolerance approach to substance abuse in government funded facilities".

HEPATITIS C COUNCIL OF VICTORIA
announces

TIME TO GET SERIOUS!
THIRD COMMUNITY
CONFERENCE ON HEPATITIS C
MONDAY 17 MARCH 2003

2nd call for abstracts

SEE THE ENCLOSED LEAFLET
in this issue of Good Liver
or for more information ring the
council or see our web site
www.hepcvic.org.au

COUNTRY SUPPORT GROUP UP, UP AND AWAY!

A new Support Group has started in **SALE**. The Group meets on the third Tuesday of every month, 2pm to 4pm at the Central Gippsland Health Service, Palmerston Street in Sale. For more details contact **Lauren** on 5143 8800 or **Annemieke** on 0438 128 919.

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coming up:

24 - 27 FEBRUARY 2003

SYMPOSIUM: PREVENTING SUBSTANCE USE, RISKY USE AND HARM: PERTH

Hosted by the National Drug Research Institute amongst four others, the focus of the Symposium will be on the quality of science underlying key assumptions and claims regarding effective prevention policy and practice across both legal and illegal drugs. For further information contact Rachael at R.J.Lobo@curtin.edu.au.

17 - 21 MARCH 2003

HEPATITIS C AWARENESS WEEK

A NEW INFECTION EVERY 32 MINUTES!

It's on again! Hepatitis C Awareness Week is the Council's major way of reaching the general public and we encourage your involvement in the 2003 Week. Be part of the activities. Any person or organisation wishing to become involved can get more information and a Resource Order Form from the Council's Web site at www.hepcvic.org.au

TO BE REALLY EFFECTIVE, THE AWARENESS WEEK AND CONFERENCE NEEDS YOUR SUPPORT!

YOUR STORY IS NEWS!

Here at the Council we are already gearing up for Hepatitis C Awareness Week in March next year. We are hoping that we can generate a fair bit of interest in the media and, to this end, we plan to send out letters, information and personal stories to metro and rural newspapers, radio and television stations.

We are looking for individuals who are living with hepatitis C and would be prepared to be the subject of media interviews. The Council can offer interested people support, training, and advice on dealing with the media.

If you are interested in helping to raise the awareness of hepatitis C in the community through telling your story, please contact **Venetia Brissenden** at the Hepatitis C Council of Victoria on 9380 4644 or country call 1800 703 003, or email venetiab@vicnet.net.au

MONDAY 17 MARCH 2003

TIME TO GET SERIOUS THIRD COMMUNITY CONFERENCE ON HEPATITIS C

As part of Awareness Week activities, this Community Conference will provide an opportunity to explore the efficacy of current strategies and canvas innovations in community responses, policy and emerging social research. Second call for Abstracts, Draft Program and Registration Form can be found at the Council's Web site at www.hepcvic.org.au

WEDNESDAY 5 FEBRUARY 2003 MEMBERS ADVISORY GROUP (MAG)

At 6.30pm at the Council offices. Call Pier or Linda on 9380 4644 for more details.

WEDNESDAY 26 FEBRUARY 2003 HECLE MEETING

This is a forum for discussion, peer support and information at the Hepatitis C Council Office. 2pm to 4pm. Contact Barb at barbdv@netc.net.au for more details

6 -10 APRIL 2003

11TH INTERNATIONAL SYMPOSIUM ON VIRAL HEPATITIS & LIVER DISEASE - SYDNEY

The registration brochure and preliminary program are now available. For your copy go to the organiser's website www.tourhosts.com.au/isvhld

next issue

CULTURAL ISSUES

Hep C affects many ethnic groups. Cultural beliefs and attitudes, language and community confidentiality can be serious barriers to accessing the health care system. What are your experiences? A page or a few paragraphs - we'd like to hear about them. Mail, fax or email to Heather - contact details page 2.

**COPY DEADLINE:
FRIDAY 24 JANUARY 2003**

2002 AGM BLASTS OFF!

I think that everybody who attended the 2002 Annual General Meeting of the Hepatitis C Council of Victoria on 26 November at the North Fitzroy Star will agree with me that it was a rather vivacious and uplifting affair.

After the formal part of the evening was done with, the three musicians who make up the band **VARDOS** were primarily responsible for the energetic atmosphere of the evening. The highlight was when some members of the audience (we have been sworn to secrecy on their identity) launched themselves into a dancing frenzy to VARDOS' obviously irresistibly bouncy gypsy sound. We would like to thank **James** and **Patricia** for their support towards the event and for ensuring that - despite the freak torrential rain of the morning - we were able to fully enjoy the plush and cosy surroundings of the venue.

A big thank you to everybody who came and made the night a memorable one and thank you to **Barry Kendall** and **Caroline Ringersma** who came to the end of their tenure with the committee. Amidst all the fun, elections to the Committee of Management took place and we are pleased to announce that the members for 2002/03 are:

Mark Stové (CHAIR) Deakin University

Jacqui Richmond (VICE-CHAIR)
St Vincent's Hospital

Jia-yee Lee (Secretary) Victorian
Infectious Disease Reference Laboratory

Michelle Thompson
Youth Projects (Foot Patrol)

Andrea Khan Victorian Aboriginal
Health Service

Mark Young Open Family

Sandy Breit Haemophilia Foundation

Ronald McCoy General Practitioner

Danielle Croall Austin Repat Hospital

Sue James School Nurse (Bendigo Area)

Clare Roberts VIVAIDS

We wish the new committee a very rewarding and successful year.

A matter of concern for us all

Imagine being told you are pregnant and that, for you, this is welcome news. A mixture of surprise and joy begin to race through your mind. Now imagine that cutting through those happy thoughts are the words of your GP saying that it would be advisable to terminate because you have hepatitis C! Distressed and determined to get another opinion you check with a gynaecologist - who agrees with the doctor. Reluctantly you attend an appointment for termination where you share your sadness over the upcoming procedure with the counsellor. Seeking clarification the counsellor rings a specialist in hepatitis C medicine. Then, a complete turn around, you see a smile and hear the counsellor saying, "You can go home and look forward to having your baby!"

THIS STORY IS BASED ON REAL EXPERIENCE...THIS YEAR.

While most of us can only imagine what any part of this story would be like, too many women in Victoria don't have to imagine...they know...and not every story has a happy ending.

There are two key issues related to pregnancy and hepatitis C. One is the health of the expectant mother and the other is establishing the risk to the child. The focus of this article is on clarifying the risk to a mother who has hepatitis C.

Since the beginning of the council's work in 1995, pregnancy and hepatitis C has been a constant feature of support calls. In the early days some people were told it was morally wrong for a woman living with hepatitis C to bring a child into the world. We can only speculate what this was based on, but it is clear that it was not accurate information about hepatitis C! Another reason given was that there was a very high chance that the child could have the virus. The percentage of risk being quoted varied from person to person but it was sometimes as high as 50% and highly inaccurate. Readers would be aware that living with hepatitis C is rarely a justifiable cause for the recommendation of medical termination and that the transmission rate of mother to baby in Australia is 5% - 8%. We are deeply concerned at the inaccuracy of information that is still being given to women with serious results.

One could be tempted to think that this is all in the dim dark past of the early days of hepatitis C. Unfortunately the experience of women across the state still includes situations where they are being told to terminate a recently diagnosed pregnancy based on "medical reasons". In a recent study of 174 women living with hepatitis C 9% women were told to abort because

they had hepatitis C.¹ This is a serious and disturbing reflection of women's experience with ramifications for the physical, emotional and psychological well being of these women, their partners and families.

Why is this still happening?

Clearly there are clear implications for the dissemination of accurate information to help GPs and gynaecologists in their clinical assessments of women with hepatitis C.

From what women tell the Council, it appears that some general practitioners are concerned about the capacity of the liver to cope due to the higher hormone levels of pregnancy and the associated pressure that being pregnant can have on the liver.

In order to have the most recent information to share with our readers about the health of expectant mothers, we sought advice from Bill Sievert, one of Victoria's leading gastroenterologists specialising in hepatitis C treatment, who wrote:

"For women with milder stages of liver disease (from whatever cause, including HCV), I am unaware of any indication for termination related to the liver. If the liver disease is "well-compensated" - meaning normal bilirubin, albumin, INR, platelets and no radiological or other clinical evidence of cirrhosis, then it would be unlikely that further liver damage would occur related to the pregnancy (this would exclude specific pregnancy related liver diseases that can occur in any woman). Serum ALT levels correlate poorly with the degree of liver damage seen on liver biopsy, so they are relatively unreliable in this instance. So I cannot see a reason that a woman with hepatitis C who does not have cirrhosis and has normal tests as described above, could not carry a pregnancy to term."

Consideration of women with more advanced liver disease was also given.

"...generally women with established cirrhosis have lower fertility, irregular menses and other factors which decrease their ability to conceive. So for women with advanced liver disease (cirrhosis and portal hypertension) from any cause, there should be a team approach to counselling from the obstetrician and the physician, given the risks to both mother and child. Having said this, there are certainly case reports of women with cirrhosis, varices, etc who have had successful pregnancies."

There is a new education program for practitioners in the medical profession being run by ASHM on behalf of the DHS in Victoria. Let us hope that it is well attended and the information on pregnancy and hepatitis C is clarified, once and for all. Readers may ask about those who do not attend an education session. A timely question! Ensuring that ALL practitioners are aware of this information is an opportunity for closer cooperation between key bodies in the sector. As much as we look forward to hearing of the safe arrival of a new baby into the world, we look forward to seeing a creative approach which results in every medical practitioner involved in the health of expectant mothers knowing the facts about pregnancy and hepatitis C.

Barb Healy Rural Community Development & Education

1. Gifford, S et al. Women living with hepatitis C. A survey of women living with hepatitis C in Victoria and the ACT. 2001.

Hep C takes the floor at ASHM conference

The Australasian Society for HIV Medicine (ASHM) attracted more than 600 delegates to its annual conference, which was held in Sydney from the 23 to 26 October.

After registration, I sat on the steps of the Sydney Masonic Centre (with my pharmaceutically embossed conference satchel) reading a document detailing ASHM's 2002-05 strategic plan, which began by conceptually framing ASHM's strategic response to HIV and 'related conditions'. In it I read that, for ASHM, hepatitis C is considered to be an "HIV related condition". That is, a condition "which plays a role in the acquisition and management of HIV". Somewhat concerned by the way that hep C was positioned, I read on with a furrowed brow.

The strategic plan stated that ASHM is in a strong position to influence the development of responses to HIV and related conditions in coming years. But on this muggy morning I was deeply cautious of hep C being viewed as a condition that further problematised HIV, rather than as a public health emergency in its own right. There should be no regard for the relative gravity of BBVs, each and every transmission is a worst case scenario. I read on, however, and was relieved to find that the remainder of the document, beyond the initial mission and vision phrasing, seemed to have a solid grasp of the need for hep C specific responses and a national hepatitis C strategy.

At this year's ASHM conference, a decision was made to address hep C as a separate issue by hosting, for the first time, a special day devoted to viral hepatitis. This day provided a unique opportunity for scientists, clinicians, health care providers and community workers to participate in a forum for the continuing development of Australia's hep C response. Clearly the day was a resounding success, it was well attended, with much positive feedback from the delegates about the breadth and quality of presentations, which covered basic science, clinical epidemiology and community/social research. In his opening address to

the conference Andrew Grulich, the president of ASHM, inferred that a name change for ASHM (presumably to ASHHM to incorporate hepatitis) was likely, but not imminent. He still seemed unsure whether a separate hepatitis C day, or an integrated 4-day conference program, was most appropriate. This division would certainly have made for a compelling conference debate!

The tensions that ripple between the community response and the medical/healthcare approach to hep C seemed to be the informal theme of most of the presentations outside the clinical stream. Miscalculating the shape of the hep C 'sector', the conference organisers placed the clinical streams in the largest rooms of the Masonic Centre, and the community/research streams in the smaller ones. While smaller rooms were crammed with enthusiastic community health oriented people spilling out into the foyers, the larger rooms had, by comparison, plenty of room for the few who occupied them.

Greg Dore delivered the first plenary session of the day, by discussing findings that identified co-factors for progression to liver disease:- alcohol consumption, elevated ALTs, older age at infection, co-infection (HIV or HBV), slight imbalance toward male gender, and possibly obesity. Interestingly, this presentation also showed evidence that in some cases, the period for the clearance of the hepatitis C virus may be longer than currently thought, up to two years after infection.

Other findings and presentations included:

- Evidence that the hepatitis C virus remains viable outside the human body for at least 2 weeks (*Bowden*)
- In overweight people with hep C, weight reduction has been shown to improve liver function, and metabolic factors associated with steatosis (fatty liver), and trials resulted in a significant lowering of ALT's (*Hickman*)
- Nurses should have more of a role in the hep C sector, such as management of side effects of combination treatment, a

broader case management role, a role in prescribing and maintaining treatment, a role in educating GPs and PCPs, an increased role in prisons, and in reducing discrimination in health care settings. It was also put forward that nurses should have a presence in all NSPs and drug and alcohol services (*Pritchard Jones*)

■ Research into HIV/HCV co-infection continues to produce important data: recent findings show that the central nervous system is very significantly affected by the hep C virus in people who are HCV/ HIV co-infected. Also, co-infected people are 2-6 times more likely to progress to liver disease and also to progress to AIDS, diabetes, insulin resistance and lipodystrophy (*Deitrich*). Other reports quantify that 14% of people with HIV are co-infected with HCV. Importantly, 19 of respondents to the co-infection section of the HIV Futures III survey believed the virus was transmitted to them through sexual contact (*O'Brien*). Even after considering the range of possible reasons for this alarming finding, it seems there is an urgent need to look in more detail at sex, blood and hep C.

■ Hep C is associated with elevated life time depressive disorders, though it is unclear whether this is causal or uni-dimensional. A study found a high co-morbidity of hepatitis C and a range of psychiatric disorders (*Gribble*), but it seemed to me that the bio-scientific framing of this study struggled with its own physical/ emotional divide.

■ The Division of Indigenous health at University of QLD has, after a comprehensive and participatory community consultation, developed a training manual, **When Sharin's not Carin**, which offers a method of working with indigenous people who inject drugs. It address cultural issues around the notion of sharing, and has extensive findings around educational attainment, prison-based initiation into IDU, as well as issues around rural and remote communities. (*Shannon*)

■ A critique of media discourses articulated the notion that in HIV editorials there is frequently an acknowledgement, through use of language, that people living with HIV are a diverse and non-homogenous group. People living with HIV are reported as having rights as patients, as being agents to their own treatments, lives and futures, and as belonging to a range of groups and

subcultures. Often these reports are framed by broader notions of social justice, quality of life, and law and politics. All of these qualities are absent in reports about hepatitis C. Hep C editorials present a singular view of a hep C population that is homogenous and without agency. To the media, 'hep C people' are faceless, uninvolved and without any sort of presence, except as subjects of medical treatment. *(Korner)*

■ A survey of Australian NSPs confirmed that young people who inject drugs are by far the highest risk group for hep C transmission. Specific predictors for this risk include young people who inject in outdoor/public spaces, are female, have been injecting for longer, have been recently imprisoned, are frequent users, and who use heroin as their primary drug *(Zhou)*.

■ Victorian research into prisons and hep C showed that prisons change the injecting behaviours of people who inject drugs. The study also found that while 40% of first incarcerations are drug related, between 80 and 90% of second incarcerations are drug related. Hence the call for a policy overhaul and the emphatic recommendation that custodial settings be utilised as public health opportunities. *(Hellard)*

The decision to host a hep C specific day at ASHM's annual conference was well founded, the high standard of presentations was enhanced by the enthusiasm of the delegates. Despite the difficult terrain encountered by ASHM in co-locating HIV and Hep C, the conference day ensured that at no point was hep C defined as a secondary issue. Indeed the day acknowledged that the rising prevalence of hep C reflects the very real need for public health strategies to reflect the ever-shifting shape of the hepatitis C epidemic.

Jen Johnson
Project Officer - Body Art

FURTHER DETAILS OF PRESENTATIONS CAN BE FOUND BY VISITING THE ASHM WEBSITE AT CONFERENCE ADDRESS IS WWW.ASHM.ORG.AU AND THEN FOLLOW 2002 CONFERENCE PROMPTS.

The names provided above are of those who presented at the 2002 conference.

MAG..nificent beginnings...

Membership Advisory Group

THE INAUGURAL MEETING OF THE MEMBERSHIP ADVISORY GROUP (MAG) TOOK PLACE AT THE HEPATITIS C COUNCIL OFFICES ON 30 OCTOBER.

It has been clear for a while now that the Council needs to be more interactive with its membership to ensure that the issues, concerns, needs and resourcing of people with hepatitis C are known and are an essential part of the direction that the Council is taking.

This is especially important as the Council works collaboratively with a range of non-government and government agencies that develop services, policies and funding for people with hepatitis C.

To facilitate this input process, the Council is assisting in the set up and ongoing resourcing of a members' based advisory group and this meeting was an exciting first step in the process of members input into the Council's direction.

The meeting was well attended and full of questions and discussion. A lot of different issues were raised including:

- The acknowledgement that MAG can begin the process of more member involvement in the future direction of the Council.
- The decision to announce the formation of MAG at the 2002 AGM
- Issues such as accountability were raised with the decision to add an extra point to the MAG Terms of Reference, being that the Hepatitis C Council of Victoria's Committee of Management is accountable to MAG by responding within a month to issues put forward by the group.
- How, why and when people want to be involved in the Council. It was suggested

that not everyone wanted to be involved in such a way (MAG) and it would be better if there were a range of ways people could involve themselves with the Council. Some examples given were: involvement during Awareness Week, or by attending more social events such as the Christmas BBQ or volunteering at the Council office.

■ A membership survey was also recommended as a way of finding out what other people would like from the Council. This was flagged for the New Year, sometime after Awareness Week in March.

It was also thought that MAG could be a place where other ideas could be generated. It was recognised that there is a lot of misinformation about hepatitis C and a general lack of information readily available to the community. Especially in regard to the range of issues that people with hep C want more information, resources, support or education about.

Council Education workers - Pier and Linda chaired and minuted this meeting. However it is envisaged that at the next meeting a convenor will be appointed by MAG members and that the group will decide on and take roles as the group develops. At future meetings, workers will attend as Council reps only, and as a group resource as needed.

From the Council's perspective we are certainly looking forward to the next meeting and all that follows.

Linda Connor
Rural Community Development & Education

MAG meetings will be held on the first Wednesday of each month. The first meeting for 2003 will be at 6.30pm on Wednesday 5 February at the Hepatitis C Council of Victoria's office in Brunswick.

If you want to become involved - call Linda or Pier at the Council on 9380 4644



my story

THIS IS ONE OF THE ORAL STORIES TOLD DURING THE COMMUNITY CONFERENCE ON HEPATITIS C HELD BY THE COUNCIL DURING NOVEMBER 2000.

This is the first time I'm giving a public speech and I'm terrified. When I was asked by Jo, if could do a presentation, I thought "Why not!" - if sharing my experience can benefit someone, I'll do it. But when I hung up the phone, I said, "My God, what have I done?" So please, bear with me if my tongue gets tangled. Also I hope that you understand my accent. Just in case you haven't noticed, I do have an accent. Anyway, I better start on the subject that brought me here.

About five and a half months ago, I started to feel that something was not quite right

in my body, my mouth started to burn, my tummy was painfully swollen and I had a constantly low temperature. I went with my problem to see the doctor I'd known since my children were little. She looked at my mouth and said, "I can't see anything", and while I was sitting on the chair she asked me to open the zip and felt my tummy and said, "I can't feel anything. So, I went out thinking that maybe it was a temporary problem. But the problem persisted and I returned to the same doctor many times, and every time she advised me to take a holiday, and every time I got more frustrated.

A friend of mine suggested going to a naturopath. So I went to one who also happened to be an iridologist, who told me there was something wrong, but that she needed a specific enzyme blood test before she could prescribe any medication.

I FELT VERY ANGRY AND HURT. VERY SOON I WAS DISCRIMINATED AGAINST AND OSTRACISED BY MY SISTER AND HER FAMILY. IT WAS VERY HURTFUL AND FROM THEN ON, I KEPT IT A SECRET.

I went back to me doctor requesting the blood test, but she refused saying "I'm not going to give you a blood test just because a stupid woman looked in your eyes!"

I then went to a herbalist, who after making my purse lighter, and my problem unresolved, suggested I should go to a dentist and have my amalgam fillings removed, because the mercury in the filling could have been the cause of my problem. (When someone feels sick, they're willing to try anything). So I went to the dentist, who told me that as soon as the amalgam fillings would be removed, I would have had immediate benefit. However, this didn't eventuate. This miracle man broke two of my teeth and to repair the damage I needed a bridge. He did a horrible job, with one tooth protruding over my lower lip, making me look like a half vampire.

Eventually I went to another dentist with my burning mouth with the hope to repair the damage done by his colleague. The second dentist sent me to the periodontist to have my gums checked. After a few sessions and \$500.00 lighter, he said

"You feel alright now don't you?". I replied "No". Then he said, "I'll send you to someone who can definitely find out what is wrong with you."

When I saw this wise man, he decided to have a full blood test done before anything else. On a Wednesday he rang me at work and informed me that I needed to see my doctor immediately because there was definitely something wrong either with my kidney or my liver. To speed up time he faxed me the results.

I rang my doctor's surgery immediately but she could not see me before Friday, and to make sure that she would have time to examine the results, I brought the test results to the surgery on Wednesday night.

When I saw her on Friday, she had the results folded in half; I proceeded to pass on the message I'd received by phone. She

looked at the results and said, "Oh, that's nothing". I pointed and said, "What about the other side?" I physically took the folded paper and turned it over, pointing to the results, and again she said it was nothing! "It only shows that your platelets are a bit down". I started to be more frustrated, confused and angry. I was losing faith in the medical profession and in particular, my doctor. The following Monday evening, she rang me and admitted she'd overlooked the liver. I was informed I needed to see a specialist, but before she would give me the referral she wanted to feel my liver. (The way she said it made it sound like a threat).

Eventually the specialist told me I had hepatitis C, and sent me to another gastroenterologist, where very coldly he questioned me about the use of drugs and tattoos, of which I denied to both. He then informed me that 40% of people from my country have the virus as a consequence of mass immunisation during the war when we were little. Personally I don't believe this either, because I am the second of seven children and I'm the only one affected by hepatitis C.

Very concerned, I rang my only sister here, and suggested she have the test. Following the result of the test, my sister rang me with a giggle in her voice, and said, "There is nothing wrong with me, and my doctor asked me "Is your sister on drugs or something?" I felt very angry and hurt. Very soon I was discriminated against and ostracised by my sister and her family. It was very hurtful and from then on, I kept it a secret.

The virus makes me feel extremely tired to the point that some days I cannot get out of bed, my head is fuzzy and at times I find it difficult to coordinate my thoughts.

All this has been aggravated, and I endure much pain followed by a very bad car accident in which the surgeon gave me half an hour to live. As you can see, I proved him wrong.

That experience removed my anger, gave me an inner strength and more positive values of life. I started to learn some coping techniques, pain control management, and also different ways to meditate, visualise and self-talk. All these tools are very helpful.

However, I am very grateful to Jo and Sandy, the organisers of the Alfred Hospital Support Group. I personally find it very good and educational. Because it gives us the opportunity to share experiences with others, it removes some of the feelings of isolation and loneliness. We gain information about the treatments available, their success, failure and side effects.

Nonetheless; whether the virus was acquired through drugs, tattoos, or like me, and many others who don't know when, where or how they have been infected, in suffering we are all the same. We need to educate the public and exercise greater compassion for each other.

And finally I wish that some medical practitioners would come down from the pedestal they got themselves on, and remember that we are not only made of various organs, but also have various emotions and feelings.

Thank your for listening. God bless you!"

With or Without?

ATTENDING COUNSELLING WITH YOUR PARTNER OR FAMILY

When you have hep C, it may impact on your partner or family. Also, the way your partner or family cope with you having hep C will have an influence on you. Therefore, you might like to think about including them in counselling sessions. Of course for a variety of reasons some people prefer not to bring their partner or family.

You don't have to have a huge "problem" to attend counselling. You can come once, a number of times or for a long period of time. Counselling can be an opportunity to "offload" in a safe environment, focus on your needs, explore your thoughts and feelings, clarify issues and concerns and work out strategies to deal with situations.

One definition of counselling is R. Woolfe's (1989)

"Counselling involves helping people to become more aware of their own internal processes so that they feel more able and confident about their own decision making. In this sense, counselling can be described as a process of empowerment; giving people greater control over their own lives. Helping people to make their choices rather than giving them advice or telling them what to do is the basic character of counselling."

The choice of whether you attend counselling with your partner/family is yours. Sometimes people include their partner/family in some counselling sessions and attend on their own if they prefer to talk about some issues privately.

Some situations where you might attend counselling with your partner/family include :

■ Disclosure issues: ie your partner is not handling your diagnosis the way you hoped, your brother stopped kissing you after you disclosed your hep C status.

■ Family issues: ie your father is having difficulty coping with the side effects of treatment, you don't seem to be as patient with the kids as you used to be pre treatment and it is upsetting your partner.

■ Relationship issues: ie your partner is concerned about transmission and it is affecting her behaviour toward you, she is finding it frustrating, because you are tired much of the time.

■ Communication issues: ie your family don't want to talk to you about your hepatitis C, you are losing your temper with your partner and don't understand why.

If you want information regarding a referral to a Counsellor, telephone the Hepatitis C Council on 03 9380 4644 or 1800 703 003 for country callers.

Sandy Breit
Hepatitis C Counsellor at The Alfred

We need a c-change

At the launch of the Victorian Hepatitis C Strategy in late October, Moira Burke, a woman with hepatitis C - a very brave woman indeed, I must add - reflected on the necessity of disregarding how people with hepatitis C contracted the virus. After all hepatitis C is a health issue, why should the route of transmission matter? Moira quickly pointed out, however, that the stigma and discrimination that go hand in hand with hepatitis C stem precisely from how people either contracted or are assumed to have contracted the virus.

INFLAMMATORY PREJUDICE

The discourse of a disease of epidemic proportions, steps well outside of the walls of medicine and science then walks off - often uncontrollably - into the socio-political realm. It is very much a case of history repeating itself: public reaction to sexually transmitted infections - such as HIV/AIDS or, in the more distant past, the plague - have always been accompanied by unbridled hysteria and inflammatory prejudice. It has not been easy for those working with HIV/AIDS to tackle the stigma attached to the virus since its appearance in the early 1980s and I do not think that, despite remarkable progress, its associated discrimination has been eliminated.

For hepatitis C the battle has proved much harder. So much harder in fact, that the **2001 NSW Report on Hepatitis C Related Discrimination** identified as a necessity a major transformation in public policy, which would blow apart the inevitability of the link between the infection and discrimination. The report - aptly called **C-CHANGE** - included almost eighty recommendations for action in areas such as health care, employment, custodial settings, insurance, funeral services, education and accommodation. A central finding cutting across all of these areas was that the most powerful driving force for the intolerable levels of documented discrimination was the inextricable link of hepatitis C with illicit drug use. What this suggests is that any call for a transformation in public policy must be accompanied by an attitudinal sea change about people who use drugs illicitly.

What is infuriatingly problematic, however, is that this discrimination is in itself one of the

major hurdles that prevent the realisation of progressive public policy outcomes.

IRRATIONAL FEAR

The examples of discrimination described in the report are widespread and multi-faceted. All of them are proven to have a profound impact on people's lives. The discriminatory behaviour of some health care professionals seriously chips away at the crucial relationship between patients and health care services in general, thus acting as a deterrent for people seeking necessary health care. Discriminatory practices and attitudes in selection and recruitment practices - both overt and subtle - produce devastating financial, social and emotional consequences for people with hepatitis C. The paucity and the substandard quality of prevention and care programs in custodial settings have detrimental effects on the health of the prison population as well as turning incarceration into a major risk factor for hepatitis C transmission. Policies and practices in the provision of insurance and of other services appear to be widely inconsistent with current natural history knowledge and clinical evidence about hepatitis C. This often leads to people with hepatitis C being denied insurance or other services on questionable grounds. Lack of knowledge, irrational fear and prejudice are present in many educational institutions leading to staff and students being harassed and victimised, their confidentiality undermined and, in extreme cases, exclusion. In the wider realm of social relations, people with hepatitis C are often rejected by their friends and families. Social isolation and a lack of connectedness with essential support networks is a common experience for people with hepatitis C.

INDIVIDUAL'S DIGNITY

Discrimination against people with hepatitis C is often not resolved by the application of anti-discrimination legislation or complaints systems. Even when systems are in place they are often inadequate to address the many and subtle instances of discrimination. For many people, the action of coming forward can be in itself an immense risk to take with unpredictable consequences. On the other hand, the existence of anti-discrimination legislation, even if not effective

in providing immediate and practical remedies, is crucial in making the community's determined assertion about the urgent need to respect an individual's dignity.

What is common to many instances of discrimination is the automatic superimposition of negative stereotypes that cluster around injecting drug users. The discrimination already experienced by people who inject drugs is extended to the person with hepatitis C. However, this goes two ways; the fears and stereotypes associated with disease, such as contagion and 'dirtiness', are extended from hepatitis C onto the whole illicit drug using population. Thus injecting drug use = hepatitis C = injecting drug use. The result of this stereotyping is that the person with hepatitis C is encouraged to feel unworthy of receiving quality care and, ultimately, undeserving of self-worth.

HIGHLY POLITICISED

As in the case of HIV/AIDS or any disease that destabilises the dominant paradigm that defines the level of deviancy or acceptability, hepatitis C is viewed as less of a health concern than a moral one. Therefore its management is highly politicised, intricately tangled in power interactions fiercely engaged in the protection of a given social order. Unlike HIV/AIDS, hepatitis C has so far failed in those elements that have been fundamental to overcoming stigma and discrimination such as political courage, leadership and the wide reach of its public education. Unlike HIV/AIDS, hepatitis C lacks the existence of a cohesive political constituency. Unlike HIV/AIDS, hepatitis C is still viewed by many as something that only 'junkies' get and does not have the feel of an epidemic that the whole community must be concerned about. Unlike HIV/AIDS, hepatitis C is not viewed as a major cause of death and - despite the large number of people living with the virus and rising rates of infection - the knowledge of its effects on the health of our community is still limited.

However as with HIV/AIDS there are many committed, determined people and community organisations wanting to recreate the ground breaking and world standard impact of Australian HIV/AIDS activism in the prevention, management and profile of hepatitis C.

**Carlo Campora, Manager
Hepatitis C Council of Victoria**

HEPATITIS C OTHER LIVER DISORDERS AND LIVER HEALTH - A PRACTICAL GUIDE

Geoffrey C Farrell Maclennan+Petty Sydney Philadelphia London 2002

I enjoyed and would recommend this book because it provides up to date information on hepatitis C and genuinely addresses many of the issues which are part of providing optimal care, support, treatment choices, improving quality of life and reducing discrimination for those affected.

Geoffrey Farrell is an acknowledged medical expert on hepatitis. He has a leading role in hepatitis treatment and research at Westmead Hospital in Sydney and in medical education on hepatitis at the University of Sydney.

Professor Farrell began writing this book to help General Practitioners to improve their understanding and knowledge of hepatitis C and other liver problems. He soon realised that there was a need for comprehensive and practical information for a much wider audience - nurse consultants, educators, people interested in public health, drug and alcohol counsellors, clinical psychologists, medical students and people personally affected by hepatitis C.

Professor Farrell is a strong advocate for the use of research evidence to inform decision making around health choices for people with hepatitis C. In this book he aims to present the evidence clearly so that it is understandable particularly for people who are unfamiliar with medical terms. He has consulted with many other experts to inform his writing and included a comprehensive reading list at the end of each chapter for those who want to read further.

Despite his desire for the book to be easily readable for a broad audience, it is definitely not a light read and is, at times, quite technical and complex. This is probably unavoidable - the liver, its related problems and hepatitis C in particular are technical and complex.

However, Professor Farrell does not shy away from the medical and psychosocial discussion and debates that are an important part of understanding this virus. Many people would find it an excellent reference book to "dip into" from time to time when questions or issues about hepatitis C arise either for themselves or the people they are working with. Others, who want a very comprehensive account may read it from cover to cover.

SO WHAT'S IN THE BOOK?

While this book covers a wide array of subjects relating to the liver, most of it is about hepatitis C

As an introduction Professor Farrell discusses hepatitis C from a historical perspective including discovery of the virus and details about its spread. He also outlines how hepatitis C infection affects people and provides an overview of testing and treatment. Importantly he talks about the personal impact associated with having the virus, the effect on the broader community and provides a brief description of government and community responses.

He then goes on to provide a detailed description of the hepatitis viruses with an emphasis on hepatitis C. For those interested in genomes, proteins, genotypes and viral replication this chapter will provide specific and accurate information. I suspect the rest of us might tune out through much of this. However the chapter does also contain more accessible information about transmission and risk factors for these viruses.

Chapters three to seven provide a vast amount of information on many of the issues related to hepatitis C. One chapter discusses acute hepatitis C infection while another provides a comprehensive discussion of diagnosis. This includes the importance and role of pre and post test counselling as well as explanations of diagnostic tests. As with all information presented in this book it is clear and factual. However Professor Farrell always manages to convey and provide insight and empathy on the personal and psychological effects having hepatitis C may have for people who are affected.

Chronic hepatitis C, including the progression of the infection, a wide and varied range of symptoms, how it affects people's quality of life and what testing means, is comprehensively addressed. There is detailed information about liver biopsy, what is involved in the procedure and interpretation of the results. Also discussed is the importance of what Professor Farrell calls "Good health messages for people with hepatitis C" in which he explores the role of diet, exercise, positive thinking, work, sleep, sex, pregnancy.

".....IT IS THE TRUST, PATIENCE, HOPE, GENEROSITY OF SPIRIT AND DIGNITY OF THE PEOPLE WITH HEPATITIS C WHICH CONTINUES TO INSPIRE AND MOTIVATE ME TO LEARN MORE AND TO DO AND COMMUNICATE BETTER"

Chapter Eight: "Treatment of Chronic Hepatitis C - treating the person" again lets us know where Professor Farrell is coming from. Here he emphasises the importance of health professionals effectively communicating with people with hepatitis C and presents this as a partnership relationship.

Wondering about the role of Complementary therapies in treating hepatitis C? Professor Farrell devotes an entire chapter to this question. He approaches it from an unusual medical perspective, looking at the reasons why so many Australians use complementary therapies, especially in hepatitis C. He focuses on herbal medicine and vitamin supplements, presenting the medical research on their effects and outlining possible toxicities.

The book's other chapters include information on Chronic hepatitis B and other liver disorders such as alcoholic liver disease, non alcoholic steatosis, liver disease in pregnancy, childhood liver problems and several other liver problems.

This is an excellent, if at times challenging book in its depth and breadth of information. It is a comprehensive, factual and accurate account of hepatitis C from a highly respected practitioner. Professor Farrell's respect, admiration, concern and empathy for people affected by hepatitis C is evident throughout the book. This is encapsulated in his introduction, ".....it is the trust, patience, hope, generosity of spirit and dignity of the people (those with hepatitis C) which continues to inspire and motivate me to learn more and to do and communicate better".

Rosey Cummings

**Health Educator: BBV's & ST's
Infectious Diseases Unit The Alfred**



Harm Reduction and Family & Friends

HOW THE HARM REDUCTION CONCEPT MAY BE VIEWED BY THE FAMILIES AND FRIENDS OF DRUG USERS

GOODLIVER IS PLEASED TO WELCOME CLARE ROBERTS, HEPATITIS C PEER EDUCATION WORKER FROM VIVAIDS. IN COMING EDITIONS SHE WILL BE KEEPING US INFORMED ON A NUMBER OF ISSUES FACING DRUG USERS.

VIVAIDS is the state-wide Victorian Drug User Organisation. VIVAIDS works under the philosophy of harm reduction and is made up of users, ex-users and people who agree with its aims. This occurs by providing education and information to people who use drugs so they can do so with the least amount of harm to themselves and others. VIVAIDS is a peer-based organisation, which provides advocacy and support for people who use drugs through various different services and projects.

VIVAIDS projects

VIVAIDS workers facilitate projects in the areas of: hepatitis C, harm reduction, young drug users, Rave Safe, overdose and pharmacotherapies (PACS*).

** Pharmacotherapies Advocacy Complaints resolution Service (PACS) is a service for people on pharmacotherapies such as buprenorphine or methadone who are having problems with their pharmacists or doctor or just want information about pharmacotherapies.*

If you'd like to hear more - tune into the VIVAIDS radio show **DRUG TALK** every Tuesday at 11am on 3CR 855 AM

VIVAIDS CAN BE REACHED AT:

**275B Smith Street, Fitzroy
PO Box 2435, Fitzroy 3065**

Telephone: 03) 9419 3633

Fax: 03) 9415 7055

Email: admin@vivaids.org.au

PACS Service: 1800 443 844

VIVAIDS generally only works with users but we do receive calls and visits from people, often friends and family members who are seeking information because someone they know uses drugs. They may want to gain an insight into the person's drug use or they may want to know how they can help them to stay safe and healthy while they use drugs. It's always great when people see the priority being the person's health and safety. Unfortunately this does not happen often enough.

The concept of harm reduction can be controversial to some people, especially parents or family members. Some people see it as encouraging drug use or that it teaches people how to use drugs. Most people, when they find out that a friend or family member is using drugs, want to get them off the drugs as soon as possible. This can prove to be much harder than they thought and sometimes it's months (or years) down the track and they're still trying to help them get off.

Harm reduction is about keeping people healthy and alive while they continue to use drugs in those months or years. One harm reduction strategy is to provide clean injecting equipment to people so they have a better chance of not contracting hepatitis C, hepatitis B, HIV/AIDS, bacterial infections, heart conditions, abscesses, septicaemia or collapsed veins. These are just some of the things caused by injecting with used or contaminated equipment.

Harm reduction is a logical concept that should not be controversial. Providing information and education to people about using drugs with the least amount of harm to themselves is incredibly valuable. It is vital that people understand the importance of this and to understand that access to information and education does not encourage drug use.

Users that have families who understand this concept are much better off than those who don't.

Users who have to hide their drug use may feel scared about having any injecting equipment in case their family finds it. This can force people to use whatever they can when they score, such as someone else's used needles/syringes, or they might have to use alone because they can't at home. This puts them at a much higher risk of dying if they overdose. Many fatal overdoses are people who have used alone and have been found too late.

HARM REDUCTION RECOGNISES THAT THE HEALTH AND LIVES OF ALL PEOPLE ARE IMPORTANT INCLUDING DRUG USERS AND THAT ALL PEOPLE CAN BE VALUABLE CONTRIBUTORS TO THE COMMUNITY.

In the end it is up to the family or friend how they react to the person's drug use and how they engage with it. Adopting the philosophies of harm reduction does not necessarily mean that family or friends have to give the person clean injecting equipment or sit there while they inject to make sure they don't overdose.

BUT...

It can mean getting priorities right and encouraging them to use safely, it means **not** searching their bags or rooms and throwing out injecting paraphernalia, **not** forcing them to use alone. Encourage the person to talk to you about their drug use so you can be sure that they are using safely. Family members can become informed on safer using strategies.

continued next page

If someone feels supported and cared for in some way it can provide them with the strength to take an active step in looking after their own well-being. Sometimes what people have to go through when they are using drugs is enormous: degradation, desperation and discrimination are three things they might experience on a daily basis and whilst dealing with these issues, the importance of their own health slips.

"Everyone tells me I'm not important and that I am scum, so why should I care about myself?" "Why should I care if I live or die or whether I get a stupid virus or not...no-one else cares about me, so why should I?"

Once people start to lose interest or motivation in looking after themselves then they might become complacent about their drug use and take more risks. They might share needles because they didn't get any clean fits or they might use the whole deal of heroin instead of half because they are not concerned about overdose.

The support and encouragement of friends and family to use drugs with the least amount of harm can help the person realise that their health is important. The encouragement to prioritise their health is not only empowering to the person who is using but also to their family and friends.

Harm reduction recognises that the health and lives of all people are important *including drug users* and that *all* people can be valuable contributors to the community.

Harm reduction strategies are used throughout Australia and have been keeping loved ones alive and healthy for decades.

Clare Roberts
Hepatitis C Peer Education Worker

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.

THE ALFRED HOSPITAL:

When: Last Thursday of every month.
Christmas Dates: 19 Dec and 16 Jan
Time: 1.30 to 3pm
Venue: Hepatitis C Clinic, 4th floor, Alfred Hospital.
Commercial Road, Prahran
Contact: Jo Mitchell 9276 2223 or Sandy Breit 92766 3061

ST VINCENT'S HOSPITAL:

When: First Thursday of every month
Time: 5 - 6.30pm
Venue: Diabetes Education Room, 4th Floor, Daly Wing, St Vincent's Hospital.
Queens Parade, Fitzroy
Contact: Lenore Kingdon 9288 2259

HEPATITIS C COUNCIL:

Contact: Pier Moro 9380 4644

Brunswick Monthly Meetings

When: Second Sunday of every month
2003 Dates: 12 Jan, 9 Feb and 9 March
Time: 2 - 4pm
Venue: Hepatitis C Council Offices.
Suite 5, 200 Sydney Road
Brunswick

Ringwood Meeting - NEW GROUP!!

When: First Saturday of every month
Time: 2 - 4pm
Venue: Ringwood Community Centre.
Bedford Park, Bedford Road
Ringwood Melway ref: 49 J8

Hep Mums Support Group

Specifically aimed at women who are mothers or mothers-to-be!
Every three months. Dates to be announced.



virtual library

from consultation, planning and pure hardwork...a catalogue is born!

On thursday 28 November, John Daye, President of PLWHA launched the Access Information Centre and Country AIDS Network Internet book and video Virtual Library Catalogue.

This initiative combines both services' resources to provide a comprehensive library catalogue that can be accessed by anyone across the state. It also includes a computerised Borrower Database sensitive to the specialised needs of our client group - eg alerts us to contact a specific client by phone rather than by mail.

It can be viewed at www.accessinfo.org.au

Call Suzanne or Jane at Access Information Centre on 03 9276 6993 for more details.

hepChat radio show

EVERY THURSDAY FROM 10AM ON RADIO 3CR [855AM]

HepChat will go to air with it's 100th program on Thursday 6 March 2003

Tune in and keep up to date with the issues facing people with hepatitis C

HEPCHAT can provide the space for sharing your story. If you wish to be involved in any way with future programs please contact Pier at the Council.



Family ties

Being told I was Hepatitis C positive has changed my life forever...and in lots of ways it's changed my family's life as well.

When I say my family's life I mean my Mum and Dad, my two sisters, my sister's kids and then I think about my Gran and the list just seems to go on and on....

Then there's my girlfriend, Donna, and her parents. When I think about all of those people it gets bloody scary and sometimes overwhelming.

I have always thought of myself as a pretty capable sort of bloke and yeah I admit I was a bit wild when I was younger. Not that I'm old or anything now...28s not old is it? I guess I've reached the time when I'm ready to settle down. Got a good job. I'm a plumber and finished my apprenticeship a few years ago and will be taking over the 'old man's' business soon.

Now this...being diagnosed with Hepatitis C was a real smack in the guts. I couldn't believe it when I was told. Hell, that part of my life was dead and gone years ago. The thing that upset me the most was the casual way it was said "and by the way you've got Hepatitis C"...then and there my life changed.

At first I went into shock. I was too young, I felt healthy. God I played football and the cricket season was just starting. I didn't want to believe it. When I look back on that time it's like a bit of a dream really.

Yeah, absolute denial.

Then fear and terror set in. I started thinking what's gonna happen to me? When am I going to die...etc etc?

I didn't want to talk to my family. Fear of rejection I suppose. Also they had an image

of me that I thought wouldn't fit with me having this disease. God I was my Gran's favourite, how will she react to me now? Just thinking about telling Donna, my girlfriend, was a nightmare. We had talked about getting married, having kids. What if she left me?

It was a bloody nightmare alright....

This scenario is not uncommon and does not relate to any particular individual but has been compiled from the many thousands of calls Hepatitis C Helpline take yearly. When a person is diagnosed with Hepatitis C, it has huge implications, not just for the individual person but also for all the other people connected with them. The impact on individuals and families is immense.

In this case it was Donna, the girlfriend, who made the first call to our service. Her initial reaction, when she was told, was one of concern for her partner, then a strong need to know what being Hepatitis C positive meant for him and how it would affect their future together. So she called our service and got as much information as possible. She was also able to express her fears for herself and whether she or others might be at risk. A service like the Hepatitis C Helpline offers callers anonymity and the opportunity to discuss some of the more difficult questions, in a safe and confidential way.

We were able to give her referrals to the Hepatitis Council to access printed information. One of the reasons she had rung was to understand enough about Hep C so that she could share accurate information with other family members.

It is our hope that armed with information, Donna was able to go back to all the families involved, tell them the facts, get married to her 'fella' and live happily ever after. The hard reality, however, is that often there are no easy solutions and as a counselling service we must always be mindful of the many people involved. All of these people will act according to their own set of values. As a service we can provide them the most up to date and accurate information, listen to them and allow them to decide for themselves.

**TO CONTACT THE HELPLINE: PHONE
03) 9349 1111 OR 1800 800 241
COUNTRY FREECALL**

USEFUL SERVICE NUMBERS

Chinese Herbalist

Lisa McPherson
Telephone: 03) 9481 8514

Counselling

Positive Counselling HIV/Hep C Inc.
at The Bouverie Centre
50 Flemington Street, Flemington
Telephone: 9376 9844
www.positivecounselling.org.au

Dentist

Martin Hall
23 Lennox Street, Richmond
Telephone: 03) 9420 1302

Employment

Options Enterprises
Suite 5, Level 8
Como Office Tower
644 Chapel Street, South Yarra
Telephone: 03) 9824 2330

Medical

Barkly Street Clinic
60 Barkly Street, St Kilda
Telephone: 03) 9534 0531

Naturopaths

Jenny Adams
Telephone: 03) 9489 8411

George Campbell
Telephone: 03) 9646 5455

Andrew Green
Telephone: 03) 9819 6680

Ondine Spitzer
Telephone: 03) 9372 0499

Gill Stannard
Telephone: 03) 9650 3419

Alison Whitehead
Telephone: 03) 9482 2205

Tattooist

Piercing Urge
1/206 Commercial Road, Prahran
Telephone: 03) 9530 2244
Web: www.thepiercingurge.com.au

FIRST SOD TURNED FOR HEALTHWORKS



The man with the shovel is State Member for Footscray, Bruce Mildenhall, watched by Western Region Health Centre CEO, Pier De Carlo at the recent Launch.

Although Health Works has been operational since January 2002, it was officially launched on 1 November at the site of the new building - across the road from its present location - at 215 Nicholson St Footscray. It is anticipated that the new location will be open for business early next year, offering an array of consulting rooms, meeting and training rooms, the WRAP office, counselling rooms, and more.

Present to 'turn the first sod' was local State Member Bruce Mildenhall, who commended the hard work and initiative of the Harm Reduction Coalition who first lobbied for dedicated drug user health care services, and stated that the issues arising from illicit injecting drug use could "only be tackled by a whole community approach". This approach is exemplified in the establishment of Health Works and similar services in other regions, which offer injecting drug users non-

judgemental, confidential and supportive primary health care and referral.

Health Works provides blood borne virus testing with pre and post test counselling, free hepatitis B and tetanus vaccinations, sexual health testing and treatment, first aid and wound care, counselling, nutritional advice, needle and syringe exchange and disposal (through WRAP), and referral to dental, physiotherapy and drug treatment services. The service also includes a health and drug safety program designed specifically for Cambodian, Laotian and Vietnamese community members. Since opening in January this year, Health Works has had over 840 contacts with service users.

Health Works can currently be found at 226 Nicholson St Footscray and contacted on 9687 5202. The service is open from 1-4pm, Mon to Thurs.

NEW TREATMENT STUDY

New 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 Jo Mitchell (The Alfred Hospital) on 9276 2223 or Sherrylene Warner (Monash Medical Centre) on 9594 5545.

AN INVITATION TO JOIN US

For a community organisation such as the Hepatitis C Council of Victoria, membership is an essential and vital component for the achievement of our goals and objectives.

There are 3 types of membership.

1. Individual: Entitles you to: one copy of Good Liver per quarter, one vote at the AGM, copies of all resources distributed by the Council.
2. Healthcare Professional: As for individual - includes 3 copies of the Good Liver.
3. Organisation: As for individual - includes 5 copies of the 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) _____

Address _____

Postcode _____

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

Telephone _____

Fax _____

Email _____

Tick one membership box. (Includes GST)

- | | | |
|----------------------|--------------------------|------|
| Individual (waged) | <input type="checkbox"/> | \$15 |
| Individual (unwaged) | <input type="checkbox"/> | \$5 |
| Professional | <input type="checkbox"/> | \$33 |
| Organisational | <input type="checkbox"/> | \$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?

LIVER CLINICS

Albury/Wodonga

Telephone: 02 6024 5255

Alfred Hospital

Telephone: 9276 2223

Austin/Repatriation Medical Centre

Telephone: 9496 2787

Ballarat Liver Clinic

Telephone: 5332 9210

Ballarat North - Dr Jon Watson

Telephone: 5331 8289

Bayside Hepatitis Clinic

(through the Alfred Liver Clinic)

Telephone: 9276 2223

Box Hill Hospital

Telephone: 9895 3333

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 5545

Peninsula Liver Clinic

Telephone: 9781 4434

Royal Melbourne Hospital

Telephone: 9342 7212

Sale - Fitzpatrick House

Telephone: 5144 4555

Springvale Liver Clinic

Telephone: 8558 9000

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

FOR MORE LISTINGS
SEE OUR WEBSITE AT
WWW.HEPCVIC.ORG.AU

COUNTRY CONNECTIONS

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 8355

Email: can@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

Annemieke Van Vliet

Mobile: 0438 128 919

Horsham - Wimmera Hep C Support

Contact: Jan Spencer

Telephone: (03) 5381 9378

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 (SG)

Contact: Dawn Stone

Telephone: (03) 5831 2012

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

Wodonga Community Health

Contact: Debbie Heery

Telephone: (03) 6022 8888

Yarrawonga Community Health

Contact: Cherie McQualter Whyte

Telephone: (03) 5744 1324

SERVICE DIRECTORY

Access Information Centre at the Alfred Hospital

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: anex@onthe.net.au

Australian Complementary Health Association

Telephone: (03) 9650 5327

Web: www.diversity.org.au

Direct Line

Drug & alcohol counselling and NSP info

Telephone: (03) 9416 1818

Free call: 1800 136 385

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) 9752 5533

Hepatitis C Helpline (Counselling)

Telephone: (03) 9349 1111

Freecall: 1800 800 241

Melbourne Sexual Health Centre

Telephone: (03) 9347 0244

Free call: 1800 032 017

Office of the Health Services Commissioner

Telephone: (03) 8601 5222

Complaints: (03) 8601 5200

Freecall: 1800 136 066

VACCHO

(Victorian Aboriginal Community
Controlled Health Organisation)

Telephone: (03) 9419 3350

Fax: (03) 9417 3871

Victorian Aboriginal Health Service

Andrea or Jimmie

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: drugsafe@vicnet.net.au