

GOOD LIVER

NEWSLETTER OF THE HEPATITIS C COUNCIL OF VICTORIA



THE MESSAGE IS STILL SERIOUS

**1 IN 100 AUSTRALIANS HAS HEPATITIS C. 1 AUSTRALIAN IS INFECTED EVERY 32 MINUTES.
MARCH 17 TO 21 2003 IS VICTORIA'S HEPATITIS C AWARENESS WEEK**

The Hepatitis C Awareness Week aims to promote community understanding of how hepatitis C is transmitted and prevented, and the issues faced by those living with the illness. The 2003 message - **Time to Get Serious** - builds on the success of 2002's **This is Bloody Serious**, and again will feature on the thousands of postcards and posters sent out to community organisations, schools and health centres around Victoria to promote Awareness Week.

It is encouraging that hepatitis C seems to be getting mentioned more in the media and talked about as a health issue in the

community. Nevertheless, it is astonishing, when approximately 1% of the Australian population is estimated to have the virus and hepatitis C has become the leading cause of liver transplants in Australia, that there is so little awareness in the wider community of what the illness consists of, how it is transmitted and how it may be prevented. Misinformation, stigma and myth still abound about hepatitis C.

Hepatitis C is the fastest growing infectious disease in Australia. 16,000 new infections occur every year. Current estimates of the incidence of hepatitis C show a 45% increase over 1997 estimates. The alarming 2002 estimates and projections of the hepatitis C virus epidemic in Australia, released by ANCHARD (the Australian National Council on AIDS, Hepatitis C and Related Diseases) have provided the impetus for the 2003 Awareness Week campaign.

The statistics are bloody serious and they require a serious response on the part of local, State and federal governments. They require a serious commitment in the form of programs, community education, funded research, maintenance of present harm reduction initiatives and funding found for

new ones. Serious changes need to occur in the area of policy, attitudes, and community awareness in regard to hepatitis C if the current prevalence is to decrease and the rising tide of new infections is to be stemmed. More also needs to be done to support the health and social needs of the growing numbers of Australians now living with a significant illness.

Late 2001 saw the release of **C-Change**, the Anti-Discrimination Board of NSW's report of their enquiry into hepatitis C related discrimination. A key conclusion of the enquiry was that discrimination against people with hepatitis C is rife. This discrimination results in part from ignorance about the virus, but more frequently "is often motivated by stereotyped responses towards people on the basis of past, current or assumed injecting drug use" (p.12).

As Moira Bourke pointed out in the previous issue of Good Liver, "the hard social issues around injecting drug use need to be tackled; not ignored, or overlooked" if "the spread of the virus is...ever to come under control". While it shouldn't matter how a person contracts hepatitis C, the complex relationship between the disease

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

Register Now!

**SEE OUR WEBSITE
www.hepcvic.org.au
or for more information call
the Council on 03 9380 4644
or 1800 703 003 country callers**

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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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FROM THE FRONT PAGE

THE MESSAGE IS STILL SERIOUS

and the highly stigmatised behaviour of illicit injecting drug use has implications for prevention initiatives as well as for those living with the virus. "Addressing hepatitis C should be a straight forward health issue" she said, "but it's not".

Prevention strategies for hepatitis C are difficult to implement as they are often at odds with attitudes, institutions, and laws that keep injecting drug use a perilous and hidden activity. Likewise people who live with the virus will often have to contend with stereotypical assumptions made about their lifestyles that impact on their ability to access support, information and healthcare.

This is why the message of Awareness Week 2003 is that Hepatitis C is a major health issue. It is also a social justice issue. People living with hepatitis C are subject to discrimination, stigma and lack of access to appropriate services. Clearly, it is time to get serious about hepatitis C.

In addition to generating and distributing promotional material, the HAPPE committee (Hepatitis C Awareness Planning and Promotion of Events) auspiced by the Hepatitis C Council of Victoria is presenting the **Time to Get Serious, 3rd Community Conference on Hepatitis C at Eden on the Park on 17 March**. There will also be information stalls at Bourke St Mall and the Queen Victoria Markets during the week, and many organisations throughout Victoria will be hosting their own Awareness Week events.

If you would like more information about Awareness Week, or would like to volunteer, check out the Program of Events on our website (www.hepcvic.org.au) or call us at the Hepatitis C Council of Victoria on 9380 4644.

Venetia Brissenden
Hepatitis C Council of Victoria

THANKS GOES TO THE ORGANISING COMMITTEE - HAPPE (HEPATITIS C AWARENESS AND PLANNING OF EVENTS)

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Department of Employment,
Education and Training

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Access Information Centre at the Alfred

Venetia Brissenden

Hepatitis C Council of Victoria

AWARENESS WEEK SPONSORS

The Hepatitis C Council of Victoria would particularly like to thank the sponsors of the 'Time to get Serious' third community conference on Hepatitis C and the Hepatitis C Awareness Week 2003 for all their support:

Conference sponsors:

The Department of Human Services, VicHealth, Roche Products, Roche Diagnostics, Slater & Gordon Lawyers, Shering-Plough and the AIDS, Hepatitis and Sexual Health Line.

Awareness Week sponsors:

The Department of Human Services, Melbourne City Council, the Victorian Infectious Diseases Reference Laboratory (VIDRL). Avantcard, Waterwheel Press, 3CR Community Radio, 3RRR Radio Station and Access Information Centre at the Alfred.

We would like to extend our sincere appreciation of their involvement - we couldn't have done it without them!



news

TV DOCUMENTARY

I am a filmmaker currently researching a television documentary on "Living with hep C" and am looking for people who might be willing to appear in this program. What I am interested in is to give a human perspective to this illness and to particularly focus on raising awareness and tolerance by also talking about the moral discrimination which is still so common. If you are open to the idea of participating, I can be contacted either by email: smp@wxc.com.au or by phone **0418 397 088**. I am more than willing to discuss where I am coming from and on what basis this program could be made. **Philippe Charluet**

KEEP AN EYE OPEN FOR THE AWARENESS WEEK EVENTS PROGRAM

Organisations all over Victoria are coming on board for Hepatitis C Awareness Week with a host of different events and activities. As soon as we can get all the info together we will get an Events Program up on our web site (www.hepcvic.org.au), so keep your eyes open and check out any of the events happening near you!

HEPATITIS C EDUCATION AS PART OF AWARENESS WEEK

WRAP will be running 8 hepatitis C education workshops for people who inject drugs twice a week from March 10 to April 4. The workshops are aimed at WRAP service users, but anyone is welcome to attend as long as they inject drugs and live in the West. **To find out more, or to put your name down to attend, contact Melissa Dent, Mobile Drug Safety Worker at WRAP. Telephone 03) 9687 5202.**



HAPPY BIRTHDAY

Aids Hepatitis & Sexual Health Line Inc invite you to join us in celebrating the 5th Anniversary of the

Vietnamese Hepatitis C Information Line (1998-2003)

For further details phone **03 9347 6133**

TWO NEW EMAIL ADDRESSES

Please note that our two rural workers have new email addresses.

You can now reach Barb Healy at barbh@vicnet.net.au and Linda Connor at lindac@vicnet.net.au.

DONATIONS TO COUNCIL ARE TAX DEDUCTIBLE

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

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WEDNESDAY 5 MARCH 2003

MEMBERS ADVISORY GROUP (MAG)

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

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 info 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 NEED YOUR SUPPORT!

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. Program and Registration Forms can be found at the Council's Web site at www.hepcvic.org.au

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

PHOTO ACKNOWLEDGEMENTS

GL would like to thank the DHS and particularly Maria Karvelas for supplying the Council with photos of the Launch of the Victorian Hepatitis C Strategy late 2002, that were used in the Summer issue of Good Liver.

Carlo's exit

I have taken the decision to break away from the Hepatitis C Council of Victoria in late February after working here for over 5 years.

This has been one of the hardest professional decisions I have made and I have to admit that it has been a very challenging process. Because of the nature of the work at the Council, one's whole life easily becomes professionally but often also emotionally involved in the issues that are dealt with within the work environment day after day. It is a great place to work and it is also persistently demanding.

My time at the Council has been an extraordinary journey on many levels. I was very fortunate to start back in 1998 as the community development and education officer. I regarded it as a real privilege to be able to play a pivotal role in establishing back in 1999 the only (at the time) and still alive and kicking support group in Melbourne for people with hepatitis C. I cannot be grateful enough to the people who shared their experience with me and the other group members and informed my work with essential and crucial information.

I was again very fortunate later to be offered the opportunity to lead an outstanding and highly committed group of workers. There is no doubt that the larger team established in early 2001 has managed successfully to ensure that the Council is now firmly on the map in Victoria. We are now clearly recognised as an organisation with wide-ranging expertise in the field of hepatitis C on a state level and are also able to contribute to policy development at a national level. This recognition has also been accompanied by more active partnerships and collaborations with other agencies in both the government and the community sectors.

As new infections continue to rise and discrimination and stigma are still hard realities that people with hepatitis C



continue to face, hepatitis C Councils need to be adequately resourced to ensure that their prevention, advocacy and support services can fully meet the needs presented by their constituency. I believe that - thanks to the fundamental, remarkable and relentless input from my team - I am handing to my successor an organisation bursting with energy and incredible potential. However, this energy and potential can only bring about results if the organisation is given the means to plan its priorities strategically and operates free of funding concerns from year to year.

I shall certainly miss the many colleagues and working partners from the (still) rather small but incredibly vigorous hepatitis C sector. I will most importantly miss working for the benefit of the many members which provide the very foundations and the drive for the organisation to continue to exist and grow stronger. Professionally I am leaving the hepatitis C sector, however I am not giving up my personal commitment to making a difference for people with hepatitis C.

Carlo Campora

DURING THE TRANSITION, BARB HEALY WILL BE ACTING MANAGER.

Challenges for change

culture, health and hepatitis C

By Minh Vo, Cambodian, Lao & Vietnamese Drug Safety Worker and Gabrielle Bennett, Community Health Nurse.

The importance of our thoughts, communications, actions, customs, beliefs and values cannot be underestimated in relation to our personal health behaviours, and our perceptions and expectations of health services and health workers.

These cultural issues along with institutions of racial, ethnic, religious and social groupings influence our health in a complex and powerful manner. Sometimes, despite considerable efforts, health workers have a limited understanding of the social and cultural dynamics that influence attitudes and health. This is particularly so in relation to hepatitis C, with its associations of blood, stigma, injecting, drug use and chronic disease.

Census data, health status surveys, consultative research data and ethnic health audits provide some evidence of the experience of culturally and linguistically diverse people in accessing and using the health system in Victoria. While awareness of cultural sensitivity and responsiveness is growing in many health services, barriers to access still remain firmly in place.

The Cambodian, Lao & Vietnamese (CLV) communities have overcome many

difficulties in the process of integration and resettlement into Australian society over the last two decades. They now face other social and health issues that reflect those of many people in the Australian community. Drug use, mental illness, gambling problems, homelessness, poverty and health issues such as the spread of HIV and Hepatitis C are growing. But statistics tell us that CLV communities are under represented in using health and drug and alcohol services.

HOW CAN HEALTH SERVICES IMPROVE THEIR SENSITIVITY TO CULTURAL ISSUES?

Cultural diversity training - the platform to build from.

Managers, coordinators and staff in the health sector need to reflect on their own cultural backgrounds, put their own and other's experiences into context and understand how cultural values and assumptions affect communication and work in health. Australia's historical context in relation to its indigenous people, colonisation and waves of immigration have a powerful influence on the situation today. An understanding of the principles of cultural diversity is essential before health workers and decision makers can bring about changes to their practice or organisational structure that will increase access and equity.

Vietnamese people often rely on traditional health treatments or spiritual treatments from traditional healers. This is particularly important when western treatments cannot offer a cure, such as with hepatitis C and HIV.

There is a strong social stigma regarding alcohol and drug use, hepatitis C, HIV, and mental illness in CLV cultures and Australian culture. The public attitude makes it difficult for people to discuss these things or access health services. It is easy to become isolated from your own community.

DIVERSITY OF STAFF

Attracting skilled staff from the diversity of community groups is one strategy that can improve the responsiveness of a service.

Staffing teams should reflect a broad diversity in cultural background, age, gender and experience so clients have a choice of service provider, including bilingual and bicultural staff. Staff from diverse communities may be in a position to act as cultural advocates or advisors to the health service.

At lunch one day, some of the staff team were discussing their family traditions and celebrations for Ramadan. So the manager asked these 3 staff to present an information session on Ramadan to all the whole health team. This increased awareness of their clients' and colleagues' traditions.

BUILD PARTNERSHIPS WITH MANY ETHNIC COMMUNITIES

Establishing trust is vital to forming any healthy relationship. It takes time, understanding and effort to build effective partnerships between health services and local cultural groups, migrant resource centers and community leaders. Invite these agencies to participate in bilateral projects. Community education can be a two way strategy that brings understanding and tolerance to CLV communities and to mainstream health workers.

Some Cambodian, Lao and Vietnamese clients don't trust government services or police as they have had negative experiences in their own countries with the authorities.

INTERPRETING SERVICES

All clients should be informed that an interpreter service is available. Often health workers make an assumption that the client's English is 'good enough'. The client may indeed have good English language skills but may need assistance from an interpreter when a complex medical consultation takes place. Health staff should be offered training on how to work with interpreters.

It's best to always use the same interpreter with a client. People can worry about confidentiality and often feel scared that their personal story will get back to their community. Introduce the client to the interpreter and check

continued next page

Challenges for change

culture, health and hepatitis C continued from previous page

that they are comfortable to proceed. Sometimes the interpreter may not be suitable for that person because of their gender, family connections or history in the country of origin.

HEALTH INFORMATION IN LANGUAGES OTHER THAN ENGLISH

There is a lack of quality consumer health information available in languages other than English. Dedicated budget provision is needed for multilingual information. It is essential to involve the target audience in the process of developing health information resources as well as accredited translators to translate written information.

CLV communities have a limited understanding of hepatitis C. They don't know how to prevent it or where to go for help, there is not a lot of information in their own languages to increase awareness.

English language pamphlets on safer injecting of drugs were translated into Vietnamese. The Vietnamese community was not asked about this idea. Some of the English words would not translate directly and the meaning was lost. The pamphlet was written in very formal language that many found difficult to understand.

CULTURALLY APPROPRIATE INFORMATION

Involving community representatives in the development of any information is essential to produce acceptable and quality information. Consideration is needed regarding language, literacy levels and preferred medium, that is, audio, written or video. The use of graphics, icons, symbols and colors conveys a message and consultation with the target audience is vital. Appropriate signage describing the health services and the availability of interpreters is important.

A pamphlet on healthy eating was produced for the Horn of Africa communities but the right people were not consulted. Many found the picture of the family dog near the dinner table offensive.

DATA COLLECTION

Collecting data regarding clients' cultural identity, preferred language and other cultural and linguistic indicators can significantly improve organisational effectiveness. Data needs to be collected in a manner that is sensitive, accurate, effective and consistent. It is acknowledged that data collection can be time consuming and frustrating for health workers and service users, however data is important to identify and measure the impact of programs and policies on cultural and language groups.

A woman in the hospital was asked her country of birth. She was born in East Timor. The data base did not list East Timor so the health worker suggested he record Indonesia instead. The woman felt offended and unwelcome.

HOW CAN PEOPLE FROM CULTURALLY AND LINGUISTICALLY DIVERSE COMMUNITIES ASSIST TO IMPROVE HEALTH SERVICES?

It is acknowledged that sometimes people from culturally and linguistically diverse communities will feel unable to influence the way a health service is delivered. However information, involvement and suggestions from service users can be a powerful impetus for change.

- Ask health workers for whatever you need.
- Explain your cultural traditions to health workers...educate them!
- Ask if there are consumer participation committees you can join.
- Fill in feedback sheets with suggestions to improve the service.

- Tell your friends and family about culturally sensitive services.
- Ask for information in your preferred language.

FOR FURTHER INFORMATION CONTACT:

Centre for Culture, Ethnicity and Health

Enquires: 9427 8766

Web site: www.ceh.org.au

Your local Migrant Resource Centre

Under M in the white pages.

Minh Vo - Cambodian, Lao & Vietnamese (CLV) Drug Safety Worker,
North Richmond Community Health Centre

Minh has worked with the Indochinese Community (Cambodian, Laotian and Vietnamese (CLV) communities) for many years in social and welfare services, and recently in the mental health and drug safety services in Melbourne.

Gabrielle Bennett - Community Health Nurse, Living Room Primary Health Service

Gabrielle has worked with vulnerable communities in Melbourne and the Northern Territory for 15 years. More recently she worked in the Department of Human Services on a project in regard to blood borne viruses and sexually transmissible infections in culturally and linguistically diverse communities.

Gabrielle can be contacted on:
Telephone: 9654 6207(office),
9662 4488 (health service)

Ask for an interpreter

DO YOU HAVE A FRIEND OR RELATIVE FROM A NON-ENGLISH SPEAKING BACKGROUND?

DO YOU HAVE A CLIENT FROM A NON-ENGLISH SPEAKING BACKGROUND?

Attending hospital appointments can be daunting for anyone and especially challenging if English is not one's first language. It is valuable as a friend, family member or professional to inform people of their rights in seeking an interpreter or translator for hospital appointments.

When people come to the hospital for medical appointments such as the hepatitis clinic, an interpreter may have been organised if the clinic is aware that one is required. If that hasn't happened it is important to know that an interpreter can be booked for the next appointment free of charge to the person attending the clinic. Having an interpreter is this person's right and obviously assists both the person and the doctor. People are also able to request a note taker, which is especially useful for people who have a hearing impairment or a translator who will translate something like a medical report from English into their first language.

Interpreters facilitate the communication from one language to another and are familiar with both cultures. Translators translate written material from one language to another and note takers write notes of the communication during an appointment.

Some people are worried about using an Interpreter, because they do not want others to know about their life or their hepatitis C. This is understandable. It is important to know that both interpreters and translators are bound by their professional code of ethics. They are not allowed to disclose any information from appointments, which means that all information remains confidential.

If you know anyone who has an appointment at the hepatitis clinic or other appointments at the hospital, please let them know that it is very important for them to understand fully what is

communicated at appointments with the doctor and other health care workers, including counsellors and social workers. It is also important that they have the opportunity to ask questions. If they are considering treatment for their hepatitis C, it is essential for them to comprehend what it involves, the process and the possible side effects before they are able to consent to treatment. Understanding the medical terminology can be difficult enough if one speaks English, let alone if English is not one's first language.

Some people like to bring family members or friends to interpret at appointments. Sometimes their doctor might even make that suggestion. This is not appropriate for a number of reasons. A family member or friend may not interpret everything, because they may be worried about upsetting the person, may not understand the medical terminology or may be feeling uncomfortable. It is impossible for them to be neutral or for them to "interpret" and to simultaneously join in the conversation with the person and the doctor. It is much better to bring your family member or friend in as a support person and for the clinic to book a professional interpreter.

If your relative, friend or client is having difficulty in getting an interpreter for their hospital appointments, they could ask to speak to a social worker who can advocate on their behalf. People who come from non-English speaking backgrounds need to have equal access to hospital services and knowing about the free interpreter service can often be useful.

**Sandy Breit
Counsellor**

**Ronald Sawers Haemophilia Centre
Alfred Hospital
Telephone: 03) 9276 3061**

MAG

MEMBERS ADVISORY GROUP MEETING

The Members Advisory Group (MAG) had its first meeting for the new year on Wednesday 5 February.

The meeting was well attended and shows the willingness of the membership of the Hepatitis C Council of Victoria to become more involved in its activities and direction.

With Awareness Week just around the corner, a lot of the discussion centred on the activities being planned for the week, with many of the people present making themselves available to help out during the week.

Other issues discussed were staff turnover, the re-branding of support groups, the need to have more information on the long term side effects of pharmaceutical treatment, the availability of hepatitis B vaccinations and a proposed survey of members' views.

The meetings will be held every month and represent a great opportunity for members to add their voices to the work of the Council, as well as being a forum to put forward views and discuss issues. If you are unable to attend but would like to stay in touch, you can contact us and be put on the MAG mailing list, either electronically or by mail.

The next MAG meeting will be held on Wednesday 5 March, 6.30pm at the Council offices in Brunswick.

MAG meetings will be held on the first Wednesday of each month. Therefore, the next meetings will be held on the April 2, May 7 and June 4.

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

Getting cultural on hepatitis C

Successfully tackling hepatitis C in culturally and linguistically diverse Victoria

Victoria is Australia's most culturally diverse state. We bask in our cosmopolitan and tolerant society, celebrating our great diversity with 43% of people either born in another country or born to parents from another country and 21% speaking one of the 180 languages other than English.

However, infectious diseases such as Hepatitis C rarely conform to simplistic political, social or geographical boundaries and can affect everybody and anybody. According to the Burden of Disease research in Victoria, there is a dearth of understanding about the relationship between ethnicity, cultural diversity and Hepatitis C. When we are talking about culture we are talking about different worlds, real complexity and often a lot of simple, but honest confusion which can make providing effective Hepatitis C services to culturally diverse communities quite challenging.

We already know a great deal medically about Hepatitis C - we have good knowledge about its replication, about how it affects our livers and about ways to make us feel better, be healthier and effectively control our symptoms to lead a normal, happy life. Our cultural understanding of the virus

however, is limited. Very little is known about the way that Hepatitis C impacts the lives of different ethnic communities and the cultural forces that affect its transmission nor how to provide culturally effective care. Despite this, some progressive Victorian universities and community health centers are however increasing their research understanding and service sophistication in working with ethnic communities on Hepatitis C issues.

In terms of simple numbers, you may think most people infected with the virus or at risk are of Anglo-Australian heritage and share a common Australian culture. However for Victoria's culturally and linguistically diverse communities this is often not the case. Within so called 'Australian society' there are many different sub-cultures that may impact on the way illness is experienced, expressed and can be treated. People have different languages, different ways of experiencing the world, different lifestyles and attribute different meanings to health and well-being. Non-English speaking people may also experience real stresses about simply 'being a minority', lack the many social supports most of us take for granted daily and are often greatly disadvantaged economically. These things can interact in a potent way to increase their risks of infection with Hepatitis C. Importantly, the ways currently used to reduce this risk may not be as effective for many ethnic people because of their cultural differences. Ethnicity directly impacts health and well being outcomes and services providers need to be aware of these cultural influences when providing services.

In Australia Hepatitis C is mainly transmitted by unsafe injecting drug use. However for people from different countries, Hepatitis C can be transmitted in very different ways depending on the culture. For example, in some cultures the virus is transmitted by the practice of cutting rituals and scarification associated transitions to adulthood. In other cultures ritualised tattooing (such as of the eye-lids) has been an identified infection source. In many developing countries with large refugee crises, badly resourced, sterile mass immunisation programs have historically been the main route of infection.

Health issues surrounding Hepatitis C are made even more complex by the often intense shame, guilt and other meanings attached to both the behaviours that lead to Hepatitis C infection such as injecting illicit drugs and being infected itself. Different cultures will also have different ways of collectively and individually responding to these types of issues. The role of the family versus the role of the individual is often a major difference between cultures and their responses to illness and health. Risks of infection may be related to several dimensions affected by culture such as behavioural risks, individual cultural practices, environmental risks, power relationships, rituals and expectations.

People arriving in Australia who do not understand the Australian healthcare system can be especially at risk for hepatitis C in a number of other dimensions. Health promotion is a major strategy in Australia's public health system which makes many implicit cultural assumptions ranging from basic ideas about self-reliance, literacy levels, communication styles such as public campaigns and group education programs at community health centers usually conducted in English. Many of these aspects of program design may need critical cultural thinking and deconstruction if they are to be as effective for other cultural groups. For example, risk and its reduction is an underlying tenet of all Australia health promotion messages in the communicable disease and other fields, but may have very different meanings for people from different cultures. Indeed, there is often no linguistic representation for the very concept of risk itself in many cultures' language systems. Understanding the cultural meaning and interpretation of risk messages by different cultural communities may offer insights into more effective, cultural specific health promotion approaches.

Generally, the issues surrounding hepatitis C and people from culturally diverse and non-English speaking backgrounds are complex, poorly understood and often poorly researched. At the health program level, currently there is very little information about the hepatitis C virus, its transmission and symptoms in a range of

continued next page

languages that reflects Victoria's cultural diversity. Despite being well intentioned, many health promotion programs may risk failure when it comes to effectively engaging people and preventing illness in culturally diverse communities.

The Center for Culture, Ethnicity and Health (CEH) at Richmond is a state-wide organisation that works with other Victorian health services in solving their multi-cultural health issues through partnerships with the community, primary care and acute health sectors. As all public health services in Victoria have clients from many cultures, services often find themselves asking how they can better help their non-English speaking clients or raise awareness of multicultural issues as part of their organisational development.

CEH engages in local research and initiates projects and analyses and develops policies and strategies, provides cultural health information and has a nationally unique multicultural health library. We

also provide tailored training and education programs on cultural health issues for health organisations such as diversity and access, equity and culture specific health issues and we develop organisational resources. CEH also provides important advocacy, advice and referrals for culturally sensitive services throughout Victoria. The Centre has recently begun building bridges with the Hepatitis C Council of Victoria in creating a dialogue about cross cultural issues facing hepatitis C services. We will be presenting at the upcoming **Time to get Serious - 3rd Community Conference on Hepatitis C** in March to the primary care sector on cross cultural issues, health promotion and hepatitis C.

David M. Farrington
Center for Culture Ethnicity and Health (CEH)

If you have any inquiries about CEH please contact us on 9427 8766, cehadmin@ceh.org.au or see our website at www.ceh.org.au

Hepatitis C and the Aboriginal community

A WORKER'S PERSPECTIVE

The health status of Aboriginal people is worse than that of any other cultural group in Australia, and our life expectancy is 15-20 years lower than the rest of the population in Australia.

The death rates for Aboriginal people are higher than the rest of the Australian population. We have higher death rates in circulatory diseases, respiratory diseases, injuries, endocrine diseases and cancers.

Aboriginal people have higher incarceration rates than any other cultural group; we even have the highest deaths in custody (for more information read the Deaths In Custody Report).

Aboriginal people are a 4th world nation - a nation, which despite being in a very rich country, lives with 3rd world conditions.

In our own country where our ancestors walked and lived for well over 40,000 years we are treated as lower class citizens, permanently last on the social scale. Job opportunities are few and far between and show in the higher unemployment rates.

Aboriginal people are constantly discriminated against. There is not one Aboriginal person (out of an estimated 320,000) in Australia who has not been discriminated against or faced racism at some time in their lives.

For an Aboriginal person with hepatitis C the opportunity for ongoing health care and health maintenance has to be seen within the boarder context of Aboriginal health in Australia in 2003.

I have been a Sexual Health Worker since 1991. I have seen many clients struggle with their diagnosis - having been told that they are positive to hepatitis C. Most of these clients were infected through unsafe injecting drug use (IDU).

We are all aware that there is stigma attached to IDU, but we cannot sit here and say that this stigma is the same for Aboriginal users and that of other groups,

whether they are Anglo Celtic or other ethnic or cultural groups. There are many extenuating difficulties faced by Aboriginal people, which are socially, economically, and physically and spiritually based.

Injecting drug users are constantly portrayed by the broader society as social outcasts, misfits and scum. So imagine how and what an Aboriginal person who is an injecting drug user feels. And triple whammy - they are now infected with the hepatitis C virus.

Can we even begin to imagine the issues faced by an Aboriginal person who is an injecting drug user with hep C? As a result of racism, stigmatisation and isolation Aboriginal people with hep C and addiction issues find it very difficult to access appropriate health care within mainstream services.

Our Aboriginal Services (health and other wise) are finding it increasingly difficult to address the broader well-being issues and concerns in Aboriginal communities. This is significantly due to structural racism and the non-recognition of the skills, experience and expertise that Aboriginal workers and services can offer. On top of this, trying to deal with the hepatitis C virus epidemic is a difficult and frustrating task, stretching already thin resources to breaking point. However, Aboriginal services and workers do the best they can to provide appropriate information, education and resourcing to Aboriginal people who are effected and affected by hepatitis C.

On a more positive note:

The Victorian Aboriginal Health Service is keen to start a Hepatitis C Support Group. If there are any Aboriginal people that have got hepatitis C and are interested in being involved, please contact Andrea or Jimi at the Victorian Aboriginal Health Service on 03) 9419 3000.

Andrea Khan
Sexual Health Educator/Health Worker
Victorian Aboriginal Health Service
Telephone: 03) 9419 3000

ITALIANS AND HEPATITIS C

HCV IS A GLOBAL EPIDEMIC AND HAS AFFECTED MANY COUNTRIES TO A GREATER EXTENT THAN AUSTRALIA.

The following is an abridged version of an article by Melissa Bagatella and Vince Fragomeli, who discuss the impact of the hepatitis C virus on Italian-Australians.

Here in Australia, it is estimated that approximately two per cent of the population (or around 210,000 persons) have been infected with the hepatitis C virus, but in Italy infection rates are thought to be higher. It is believed that middle aged and older Italians contracted the hepatitis C virus through non-sterile medical and dental procedures, blood transfusions and intravenous treatments before 1975 - when single use disposable syringes were introduced.

In Italy, especially after World War II, medical treatments using intravenous injections (injection of medicines into the vein) were fashionable. It was common practice to administer intravenous injections of calcium, iron salts, tonics, antidepressants, vitamin C and anti-ulcer treatments, either at home or in hospital. Transmission of the hepatitis C virus may have occurred during the course of such treatments as inadequately sterilised equipment was used for the injections.

Statistics have shown that Italian men have a higher rate of hepatitis C infection than women do. One explanation for this is that men may have been exposed to contaminated medical equipment during their clinical examination whilst participating in compulsory military service.

The inability to screen donated blood for hepatitis C before 1990 has meant that people have been infected through blood transfusions. In many cases transfusions were given to women who experienced severe blood loss during childbirth, as well as men who sustained major injuries in accidents. In addition to this, a common

practice in Italy in the 1960s was to give a few millilitres of blood (as a transfusion) to underweight or pre-term babies.

Furthermore, it is conceivable that many Italians during the process of migration were vaccinated using contaminated equipment and therefore may have been exposed to the virus.

It is believed that the transmission modes described above are responsible for the hepatitis C infections seen in older Italian-born Australians today.

Melissa Bagatella is Hepatitis CNC at South Western Area Health Service, and Vince Fragomeli is Clinical Trial Coordinator at the Nepean Hospital, both in NSW.

Abridged from an article that originally appeared in The Hep C Review, edition 38. Our thanks to Hepatitis C Council of NSW for permission to reprint.

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Nousbaum, J.B., et al. *Hepatitis C Virus Type 1b (II) Infection in France and Italy*. *Annals of Internal Medicine*, 122(3), 161 -168.

Roffi, L., et al. *HCV Genotypes in Northern Italy: A Survey of 1368 Histologically Proven Chronic Hepatitis C Patients*. *Journal of Hepatology*; 29:701-706.

Cambodian C-Community

The Council is fortunate in its opportunity to work with Mr Man Yip, a student in a Master of Arts in Public Health, on the hepatitis C Cambodian Community Prevention Program.

The goals of this program are:

- To increase awareness around hepatitis C among the Cambodian community, especially young people.
- To reduce vulnerability to hepatitis C by increasing knowledge about risk factors around the transmission of hepatitis C, particularly targeting young people.
- To reduce discrimination, stigma and marginalisation within the Cambodian community.
- To inform those infected and affected by hepatitis C of the services and resources available to them.

The project will focus on the Cambodian community in the South Eastern suburbs of Melbourne and has the full support of the City of Greater Dandenong.

Other participating organisations include the Cambodian Association of Victoria, Greater Dandenong Community Health, Cambodian temples, Cambodian Student Federation, Cambodian Womens Group of Victoria, Khmer Community of Victoria and the Dandenong and Springvale Community Health Centre.

The project will conduct a number of focus groups, interviews, forums and training sessions with key stakeholders and the Cambodian community.

A range of written materials will also be produced as well as having feature spots on the Cambodian language program on SBS Radio.

If anyone would like more information on the project they can contact Mr Man Yip at kignmann@alphalink.com.au, Mr Geoff Fraser at gfrase@cgd.vic.gov.au or Pier Moro at the Hepatitis C Council.



spotlight on Vietnamese helpline

Melbourne proudly boasts one of the most culturally diverse communities in Australia, comprising people from many ethnic and cultural backgrounds.

There continues to be debate as to whether people from culturally and linguistically diverse communities benefit best from services delivered through ethno-specific or conventional services. There are strong arguments both for and against; however, we believe that the focus on the decision needs to rest with the community with respect to what is best for them, and not only with service providers. Only through collaboration between the sector and the communities will best practice be achieved.

The Hepatitis C Helpline was established in Victoria in 1995 in response to the need for information and counselling in the general community. This service has been very successful but provides insufficient access for people who may have a limited understanding of English. People from non-English speaking backgrounds require access to services, which, at least, need to match those accessible to the mainstream. There is often an increased need for accurate health information and access to services amongst marginalised groups, especially those who may experience

đường dây giúp đỡ bằng tiếng Việt 1800 456 007
đường dây giúp đỡ bằng tiếng Việt 1800 456 007

either cultural, language or education barriers.

As we moved through the nineties it became evident that our practices in delivering services and information to the Vietnamese community, with respect to such health issues as hepatitis C and harm minimisation, needed to be more effective. It was an area that required priority attention. In response to this perceived need the Hepatitis C Helpline expanded its service to include the first ethnic-specific telephone information line in 1998. Extensive consultation with Vietnamese welfare, community and health services helped in the development and formation of this service.

The Vietnamese Hepatitis C Information Line was officially launched in May of that year. The line is a pre-recorded information service, in Vietnamese, that offers multiple options to the caller. It has the advantage of being confidential, affordable and immediately accessible. Because the pre-recorded service is non interactive, it has the benefit of complete anonymity. This overcomes one of the prime cultural barriers that might otherwise prevent someone in the Vietnamese community accessing any information about hepatitis C.

The service aims to increase awareness of hepatitis C, provide information about the ways in which it is transmitted, and to supply the Vietnamese community with approaches to harm reduction. The general cultural norms, knowledge and attitudes within the Vietnamese community suggest that information that is spoken in their own language and that is culturally sensitive to their unique needs, is more readily absorbed.

The stigma and discrimination attached to people who have hepatitis C is often due to being identified as injecting drug users. This perception affects all communities, but in the Vietnamese community this often carries a particularly profound social shame and sense of dishonour. This cultural sensitivity, coupled with other short-term and long-term forms of

disadvantage reinforced the idea that a different strategy needed to be formulated, one that would meet the unique needs of the Vietnamese community. This information line was one of many approaches adopted in the community sector.

The line has been in operation for nearly five years and it continues to be actively used by the community. The annual call rate has steadily increased from around 450 in the first year to approximately 1500 in 2002. The first major review of the service is almost complete, with regular updates planned in the future. We are currently investigating a further option that will allow callers to share some personal details so that we can more effectively evaluate the service.

One of the successful outcomes of the introduction of the Vietnamese Information Line has been a steady increase in the number of people who also use the Hepatitis C Counselling Line via the Telephone Interpreter Service. Telephone counselling is an effective instrument because it permits callers to be empowered in a direct and accessible way.

We are currently exploring the further option of providing the opportunity for people to talk to a bilingual counsellor in their own language.

We look forward to continuing to develop and improve the service we offer to the diverse cultures that exist in our community by exploring the potential of utilising and adapting the current infrastructure into other languages. As we look forward to celebrating the 5th anniversary of the service, we would like to thank all those involved in the development and ongoing success of the Vietnamese Helpline.

Alex Nikolovski
Hepatitis C Help Line
Counselling Line: 9349 1111
Country Freecall: 1800 800 241

...and I know for a fact that people are not treating themselves as they should be because they're scared of the next virus...

my story

CHARLIE* IS A MAN WITH HAEMOPHILIA WHO CONTRACTED HEPATITIS C FROM THE BLOOD PRODUCT HE USED TO TREAT HAEMOPHILIA.

In this interview, Charlie shares his ideas and experiences of living with hepatitis C.

Can you describe what it was like when you were told you had hepatitis C?

Charlie: The problem was, I had been through a number of years worried about getting HIV and when I was told I had something that was non-A non-B and not to worry about it, and eventually told I had hep C I freaked out. There was no pre- or post-test counselling, which may have made a difference, or may not. It might have prepared me, that's the only thing. Yeah, I freaked out, fell apart basically, because I wasn't prepared for it.

How were you told that you had hepatitis C?

Charlie: I was told in the doctor's office. I had my tests, I went to the doctor's office, he said "you've got hep C". I said "what can I do about it?" He said "nothing really". And then I went home and thought about it, and freaked out.

I became withdrawn, depressed, it broke up my relationship. I wasn't working. I had nothing to really grasp onto. Because I wasn't working, I had nothing really

substantial in my life at the time. It was being not prepared for it, I think, was the biggest thing.

How long did that "freaked out" period last for?

Charlie: Up to three months. I knew what was happening. People were saying "get help, get help". I had to get to a stage where I thought it would be of use to me. I had to get to the lowest of the low basically. And then when I was ready for help I sought it. I saw someone five times, and then I put it in perspective basically. Putting it (hepatitis C) in perspective is the main thing. Life goes on, there's f*** all you can do about it.

How long ago did you contract the virus?

Charlie: I would say over twenty years ago.

And how do you feel about the way you contracted the virus?

Charlie: Angry.

Still today?

Charlie: Um, yeah, cause you don't have anyone to blame. No one is willing to take that on. HIV was a very big issue. This is a bigger issue, because of the numbers. Not the virulence of the virus etc, but the problem is the long term implications aren't seen like they are with HIV. With HIV you've got immediate implications with viral loads and things like that. But the long term implications with the physical damage, the mental implications I think are fobbed off to a certain degree. And that was the main implication for me.

What impact has having hepatitis C had on your life?

Charlie: Socially, yeah. I'm somewhat wary of getting involved in relationships, and sex and things like that. Big things, to be blunt. My friends and everything like that - no worries at all, because we talk about it. But I guess it attacks your masculinity if you want to be blunt about it. And yeah, that's a problem.

Family, no problems. Some don't understand, some don't ask, but that's their problem. My attitude is, if you want to ask, I'll discuss it, and I've got no

problem. Whoever's discussing it, I can put up my side of the story, and a bit more education than what they were looking at originally, which is none. And the one's who don't ask, can come to their own conclusions, basically.

Work wise, no impact. I'm quite happy to discuss it with people and if they've got a problem, that's their problem - nothing I can do about it.

Do you find you ever have to take time off work because of symptoms?

Charlie: Not from hep C. Um, general malaise, I just get tiredness, things like that. But I think that is associated with having haemophilia too, because that is pretty stressful.

Has having hepatitis C changed your outlook on life?

Charlie: Yeah. But not as significantly as if I had hepatitis C and no haemophilia. Because with haemophilia you have to think about what you do. Hep C you've got to think about things like binge drinking, but I don't drink. That's the main implication.

What sorts of things do you think about when deciding whether to tell someone your hepatitis c status?

Charlie: To be blunt, I don't really care. It's their problem. But, it's the way they will gauge you afterwards I think is the main thing. But, it's a fact of life. That's how I look at it. Before I was a bit paranoid about telling people, but now, it's a fact. It's a part of me, and if they can't accept it, if they're not prepared to ask questions - that's their problem. I'm willing to talk about it. I'm not embarrassed to talk about it, so, I'm quite happy.

What sorts of reactions have you had from people when you've disclosed your hep C status?

Charlie: Surprise, 'cos automatically they think you are an intravenous drug user. But it's good to educate people saying there are a whole gamut of people who have hep C. Not only people involved in injecting drug use. It's people who had blood transfusions and all of that sort of stuff, even some that have injected drugs

twenty or thirty years ago. You've got to understand that you can't compartmentalise it. You've got to take each person as an individual. It's really important. Easier said than done. We're all pretty judgemental. I include myself in that.

That's the way it is. Some people won't say how they're feeling, but they are really shocked and disgusted by it. But that's because they can't put themselves outside their little circle and understand that people have to deal with certain things. Some people more than other people.

Do you think that stems from fear and ignorance?

Charlie: Yeah, fear, ignorance and conditioning. One hundred percent. What they do not understand they fear. For attitudes to be changed, they've got to be informed.

Do you find that with people who initially have a bad reaction, if you give them information that their fear is lessened or have they already made up their mind?

Charlie: Some have made up their mind, but others who are willing to listen, and not just asking because they feel they have to ask. Depends really where they are coming from. Some don't give a stuff. If they don't give a stuff...but you can see their perspective. That's the way it is.

Do you experience any symptoms from hepatitis C?

Charlie: I would say, tiredness, irritability, depression, and the occasional twinge of pain in my liver - and that's really very minor. And it's just a matter of getting it in perspective, isn't it.

How do you do that?

Charlie: Be aware of it, to start with. I try not to get myself overtired. I try not to put myself under too much stress. And the depression, and that's related to stress as well. Yeah. I'm well aware of the impact that they do have, and try to reduce them. And you generally don't feel too well anyway.

Is it helpful to be able to recognise the symptoms as hepatitis C related?

Charlie: It's good, it's good because it doesn't mean there is something seriously wrong with you as a person. Although I think looking back, they could be justified in a number of ways. Everyone has stresses in life, but these are additional exacerbations of those, if you want to look at it that way. And that probably blows things out of proportion to a certain degree, I s'pose. Time will tell.

How is your hepatitis C managed medically?

Charlie: I take a livatone tablet twice a day, actually I only take one a day now. I have regular blood tests. I have regular annual ultrasounds. I don't drink. I have had combination therapy offered to me, and if I found that my symptoms got worse, or I'm showing signs I'll do something about it. But till then I would not like to, because it would interfere with work. And just being out of work is bullshit. You want to be participating in society, you know.

So when you are thinking about treatments, the things you are thinking about are the impact it is going to have on your work?

Charlie: Yeah, and my lifestyle for six months. It's a big chunk of your year to take out, and I'm going to need a knee replacement at some stage and that will be a big chunk of time off work too. I think that's very important. It affects my mobility.

Six months is a long time, and no one likes getting up in the morning to go to work. It would just give me another excuse, and I don't want that. If it could be fitted in easier...

What about the success rate of this treatment. Does that affect your decision to go on treatment? If there was a treatment that took 12 months and made you feel crappy during that 12 months, but had a 100% sustained response, would you go on it at this stage?

Charlie: No. I feel the combination therapy has a high success rate if you're on it for long enough. It's the time. And the side effects, and the result that you

have to live with on a day to day basis. It's a long term process where I think, the time is not right for it.

Has contracting hepatitis C had an impact on the way you think about your treatment products for haemophilia?

Charlie: Yeah. I'll be genuine, and I'll say this, speaking on behalf of most of the guys. As to hep C, and HIV, and whatever other viruses are out there. You pick up your product every time you need to have a shot, and you think "what the hell am I going to get this time?" And I know for a fact that people are not treating themselves as they should be because they're scared of the next virus. People have told me that in the last six weeks. And I can't believe it, because these are mature, responsible individuals. And they are still impacted by these viruses of our products. And there is no viable solution in the new product being touted.

What is the answer?

Charlie: Recombinant product. Totally new product. Have something that is not made from blood. A totally recombinant product will allay, I would say, eighty plus percent of fears that people have. And using the same product - the box hasn't even changed since people got hep C and HIV from this thing. It says high purity. It's not high purity, it's low purity. It is significant. I mean, it doesn't bother me cause I know I've got to do it, and hey, side effects... I've got to do it. I'll deal with it when I have to. But I know guys that are wavering whether to treat or not treat which causes long term social impact on those people. And a cost to the government. And these people aren't being as productive as they could be, as normalised.

**Charlie is not the interviewee's real name. It has been changed to preserve his privacy.*

Abridged and reprinted with thanks to the Western Australian Haemophilia Association.



MULTICULTURAL RESOURCES

Finding good information on hepatitis C has become a lot easier in the last few years. But what if the person with hepatitis C doesn't speak English? There is a whole range of helpful detailed brochures that have been created to support the person with hepatitis C to understand what is happening, tests and treatments, and giving ideas on what to eat. They may have nice pictures and good information, but unless there is an interpreter to go through them with the person, their contents may remain a mystery.

Even if there were enough funding available to translate all of the brochures into many languages, there are many other issues to deal with. Sometimes a simple translation of a brochure from one language into another does not help with other problems the person may be experiencing. They may not understand how the health system works in Australia. They may have different beliefs about health and illness to the doctors and nurses caring for them. These are all very real issues in Australia and people preparing health information on hepatitis C have been struggling with how to deal with them.

It can be hard enough to handle the complexities of the public health system and specialist treatment when you speak English and have lived in Australia all your life. If a person has lived in an unfriendly relationship with government in Australia or in another country, they may be very

wary of using the health system at all. They may be concerned that so much information is being collected about them and have many questions. Why are they being asked to submit themselves to ongoing procedures? Why do they need to see a specialist? Why does the nurse want their blood? What is the clinic going to do with it? What will happen to them if they take these tablets and injections? How much will it cost? Will the authorities put them in jail if they can't pay?

What do people believe about health and illness? In many countries a person may be treated in a traditional health system, such as Traditional Chinese Medicine where illness caused by liver disease is thought to show that there is a disharmony triggered by Toxic Heat and Pernicious Influences. If that is the way the person understands how illness works, it can be hard for them to get their head around a type of medicine that is believed to make them better by fighting a war against a virus in their blood.

MULTI-LANGUAGE RESOURCES

Providing information in these circumstances can be a complex business. So, how are the local agencies going about developing information on hepatitis C for people from culturally and linguistically diverse backgrounds?

The Victorian Department of Human Services has a basic and straightforward fact sheet on hepatitis C, which has been produced in 12 different languages and is available on their web site. It covers questions that are common to many cultures and also alerts people with hepatitis C to their legal rights:

HEPATITIS C: THE FACTS

<http://hna.ffh.vic.gov.au/phb/9904043>

Languages: Arabic, Bosnian, Cambodian, Chinese, Croatian, Dari, Greek, Italian, Pashtu, Spanish, Turkish, Vietnamese

The Multicultural HIV/AIDS and Hepatitis C Service in Sydney has also produced a simple fact sheet on hepatitis C in 9 languages. The service is very conscious of people's uncertainty about the health

system. Their fact sheet lets people know where to go for health services and gives brief pointers on what to expect. NB - contact numbers are for NSW. The fact sheet is available on their web site:

HEPATITIS C: UNDERSTANDING IS THE ANSWER

<http://www.multiculturalhivhepc.net/English/hepc>

Languages: Arabic, Chinese, Croatian, Indonesian, Khmer, Serbian, Spanish, Thai, Vietnamese

The Service also has a multi-language resource on hepatitis C treatments in the pipeline.

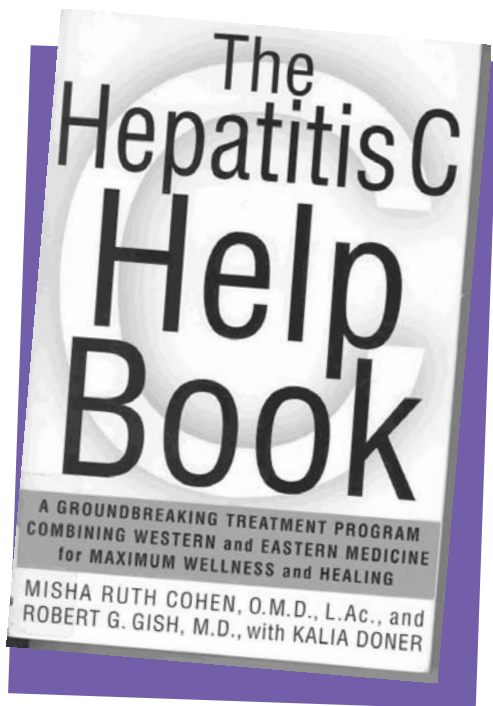
If someone would like to work through any of the English-language resources on hepatitis C in their own language, they can make arrangements with the Access Information Centre for an interpreter to be present. Anyone who would like to organise this should contact the Access Information Centre and make an appointment.

Community agencies, such as the Hepatitis C Council of Victoria and the AIDS, Hepatitis and Sexual Health Line, feel that it is important to work closely with the ethnic community they are trying to reach so that information is appropriate. For example, through its research the AIDS, Hepatitis and Sexual Health Line found that Vietnamese-speaking Australians preferred to get information on hepatitis C risk over the telephone. As a result they developed the Vietnamese Hepatitis C Line with recorded information in Vietnamese.

VIETNAMESE HEPATITIS C LINE: PHONE 1800 456 007

As part of the Victorian Hepatitis C strategy for 2002-2004, the Victorian Government is developing a new project to meet the needs of people from culturally and linguistically diverse backgrounds. The aim of this project is to work with and empower these people and their communities so that they are more able to access information and health services relating to hepatitis C, HIV/AIDS and sexual health.

continued next page



DIFFERENT UNDERSTANDINGS OF HEALTH AND ILLNESS

To bridge the gap between Western Medicine and Traditional Chinese Medicine a team of specialists in the US have produced a book on a treatment program for hepatitis C that combines both types of medicine. Their book explains the approach of Western and Chinese Medicine to hepatitis C and describes the treatment from each. It is in English (of course!) and can occasionally be technical, but is mostly a very interesting read:

THE HEPATITIS C HELP BOOK BY MISHA COHEN AND ROBERT GISH.

St Martins Griffin: New York, 2000
(available for loan from the Access Information Centre)

New resources are being developed all the time, so keep in touch if you have an interest in the area.

Till next time...

Suzanne O'Callaghan
Access Information Centre At The Alfred
Telephone 9276 6993
Fax: 9533 6324
Email: access@alfred.org.au
<http://www.accessinfo.org.au>

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.

THE ALFRED HOSPITAL:

When: Last Thursday of every month.
Coming up: 27 March; 24 April; 29 May.
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:

For anyone with hep C - not just those on treatment.
When: First Thursday of every month
Coming up: 6 March; 3 April; 1 May.
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
Coming up: 9 March; 13 April; 11 May.
Time: 2 - 4pm
Venue: Hepatitis C Council Offices.
Suite 5, 200 Sydney Road
Brunswick

Ringwood Meeting - ALL WELCOME !!!!

When: Monday 17 March
Time: 6.30 to 8.00pm
Venue: Room 3 & 4
Central 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!

Dates to be announced. Contact Pier at the Council.

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

Naturopath/Psychologist

East Wimmera region
(*Birchip, Wycheproof, St Arnaud*)
Phil Blackwood
83 Wood Street, Donald 3480
Mobile telephone: 0403 625 526

Tattooist

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

THE IMPACT OF HEALTH PROFESSIONALS' KNOWLEDGE AND ATTITUDES TOWARD HEPATITIS C

My name is Jacqui Richmond and I am employed as the Victorian Hepatitis C Educator at St. Vincent's Hospital. I am responsible, with my colleagues for educating health professionals across Victoria. As a result of my work-related experiences I am conducting a research project looking at the experiences of people with hepatitis C in the health care system as well as the knowledge and attitudes of health professionals' toward caring for people with hepatitis C. The following article is an overview of my research project. I believe that the results will improve the health care experiences of people with hepatitis C.

HEALTH PROFESSIONALS' KNOWLEDGE OF HEPATITIS C

I decided to do this research because as a nurse, I have seen how people with hepatitis C are treated in healthcare and community settings. After reading the literature I found there is a lack of hepatitis C-specific research relating to health professionals' hepatitis C knowledge and attitudes and the impact these attitudes have on people with hepatitis C. Many researchers have investigated the blood borne virus knowledge of doctors, mostly general practitioners (GPs). These studies showed that the level of understanding about hepatitis C varied between doctors, particularly there was confusion about the differences between hepatitis A, B and C¹, the impact of hepatitis C on quality of life² and the support needs of people with hepatitis C³. General practitioners have a significant role in the management of hepatitis C⁴, however, if their knowledge is insufficient, their ability to care and provide support for people with hepatitis C will be limited.

Blood borne virus knowledge of other health professionals has also been studied. Nurses are important because they are often viewed by the general public as compensating for the behaviour and dismissive attitudes of their medical colleagues and hence seen as more compassionate⁵. An Australia-

wide survey investigated the knowledge and attitudes of 1557 registered nurses towards hepatitis C⁶. Thirty six percent of nurses considered they were well educated about hepatitis C, however, they demonstrated an inappropriate understanding of the disease and infection control procedures⁶. Inappropriate clinical practice was demonstrated by 25% who believed that people with hepatitis C should be cared for in isolation; a further 18% thought people with hepatitis C should be identified with red-coloured armbands. In terms of their knowledge of the disease, 56% thought hepatitis C was a mutation of hepatitis B⁶. These results are important because they demonstrate that nurses have inadequate levels of hepatitis C knowledge and inappropriate attitudes toward hepatitis C.

The hepatitis C knowledge of other groups such as dentists, social workers, drug and alcohol workers, pharmacists and complementary therapists remain largely unexplored. Without an adequate understanding of health professionals' ability and competence to participate in a caring, supportive and educative relationship with people with hepatitis C, it is difficult to develop education strategies and implement policies to improve the quality of services for people with hepatitis C.

KNOWLEDGE OF PEOPLE WITH HEPATITIS C ABOUT THEIR DISEASE

In general, an individual's perception of their disease will influence their health behaviour, willingness to access services and potentially their recovery. Burrows and Basset (1996)⁷ conducted a needs assessment of 100 Australians living with hepatitis C and uncovered an urgent need to educate health professionals about hepatitis C because 'doctors and most other people in authority [have] very little knowledge or understanding of the virus and its effects'. In their search for information, many people with hepatitis C are given contradictory advice related to prognosis, treatment, transmission and testing, by health professionals.

IMPORTANCE OF ATTITUDES

The influence of attitudes is particularly important in a health care setting considering that health professionals are a source of advice and information. 'The ... attitudes of [health professionals] are worthy of investigation, because in the face of uncertainty and partial evidence, [health professionals] must make important choices about caring for ... patients'⁸. Their health care decisions are often influenced by their attitudes. Inappropriate attitudes can result in behavioural inconsistencies, biases and potentially stigmatising actions during contact with the patient.

ATTITUDES TOWARDS IMPLEMENTATION OF INFECTION CONTROL GUIDELINES

Infection control guidelines are enforced in health care institutions to protect the health and well being of staff and patients. However, research indicates that apathy towards personal protection is wide spread^{9,10,11,12}. Judgemental attitudes about people with blood-borne viruses occur frequently and highlight the impact of lack of knowledge and inappropriate attitudes on behaviour in a healthcare environment^{11,13}.

THE RESEARCH PROJECT

The purpose of my research is to explore the impact of health professionals' attitudes toward hepatitis C on the delivery of care for people with hepatitis C. An estimated 210,000 Australians are currently infected with hepatitis C; hence health professionals are likely to care for people with the virus at some stage in their careers. A survey will be distributed in March/April 2003 to people with hepatitis C, nurses, general practitioners, dentists, pharmacists and complementary therapists in Victoria. The results will help to develop hepatitis C education strategies for health professionals because changing health professional's attitudes, rather than relying solely on the transfer of new medical information, will improve health care for people with hepatitis C.

continued next page

100 shows for Hepchat

If you have any concerns or comments about the proposed research, please contact Jacqui Richmond on 03 9288 3586, 0407 865 140 or email: richmoj@svhm.org.au.

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HepChat, the Council's groundbreaking radio program, celebrates its 100th show on 6 March. HepChat was, and still is, the only radio program in Australia that is solely dedicated to the issues around hepatitis C.

The program was developed with the idea of giving a voice to people with hep C, to raise the profile of the issues involved, and to act as a central point for all the various services that exist around the virus.

In its first 100 shows, HepChat has had many people with hep C recount their experiences and so has helped to lift the veil on some of the myths around the virus. By having people tell their stories in their own words, the program has helped to bring some humanity back into the debate.

HepChat has also not been scared to tackle some of the more political issues about discrimination and drug law reform. The debate around hep C is inextricably linked with the issues of people injecting drugs illicitly. HepChat has consistently argued that hep C is a health issue and that people with, or assumed to have, the virus have the same human rights as everyone else.

One of the focuses of the show has been to highlight the services that are available to people in the health and welfare sectors. This has allowed HepChat to play a part in the ongoing efforts to bring better and more coordinated services to people with hep C and/or people at risk of contracting the virus.

We want HepChat to continue bringing you the news and issues for another 100 shows so if you are interested in participating, publicising an event or want to discuss issues, we would welcome your contribution. You can contact Pier at the Council on 9380 4644 or emailpmoro@vicnet.net.au

**LISTEN TO HEP CHAT, EVERY WEEK
BETWEEN 10.00AM AND 10.30AM
ON 3CR RADIO, 855 AM.**

TELEPHONE COUNSELLING TRAINING COURSE

Volunteers Wanted

We seek mature minded people to train as volunteers to staff our confidential telephone counselling service.

All volunteers are provided with extensive training that is both enjoyable and rewarding.

Contact Heather or Alex on 9347 6133 for further information and to obtain an Application Form*

*Applications close 5pm Friday 14 March

Selection Day is on Sunday 16 March



Living Room is a primary health service with doctors, nurses, and specialist health workers. All of our services are free, confidential, and best of all - 'user friendly'

Living Room welcomes injecting drug users, people who are homeless, and anybody in need of basic health care.

Feel free to drop in for a chat, or to just chill out. We provide:

- Testing for hepatitis C and HIV Hepatitis B vaccinations
- Testing for sexually transmitted infections
- Pap and pregnancy tests & contraception
- Vein care and wound care
- Safer using advice and information
- Housing information and referral
- Counselling
- Healthy eating info
- Interpreter
- Chill out space

To find us on the street you can ask the Foot Patrol, or call us:

Lyn or Gabrielle
(Nurses)
0425 746 013

Andy
(Drug Safety Worker)
0425 779 755

Free call to
Living Room:
1800 440 188





Culture, language and drug use

WORKING WITH CULTURALLY AND LINGUISTICALLY DIVERSE USERS

There are many barriers in working with people that use illicit drugs. For example, the illegal nature of some drugs, the discrimination suffered by illicit drug users and the underground nature and the stigma associated with illicit drug use, to mention just a few.

At VIVAIDS, we are often able to access individuals, groups and networks of users by virtue of being the drug user organisation. However, one group that we still have not been able to reach and work with are users from culturally and linguistically diverse backgrounds (CLDB). This is not to say we haven't tried, but the barriers to this group's participation and access to the D&A services are too great without a collaborative approach that incorporates this group as active participants. Language barriers and unfamiliarity with the system seems to be the main issues for this group. For the sector, the problems are often a consequence of lack of funding, compounded by a lack of real commitment to developing services, initiatives and intervention that acknowledge people's differences and uniqueness.

Research indicates that CLDB communities are at greater risk of acquiring blood borne viruses, due to poor access to preventative information and services, and low English skills which prevent people becoming as well informed as mainstream groups (Larson, 1998).

Acquisition of hepatitis C in identifiable CLDB communities is often the result of behaviour associated with injecting drug use. Despite the existence of programs and services aimed at reducing the harms associated with injecting drug use, (especially the transmission of blood borne viruses within mainstream Australian

populations), the concept of harm reduction has not been embraced with the same energy by people from diverse cultural and languages backgrounds. Too often users from CLDB communities find themselves marginalised from their own cultural group and community by virtue of their drug use.

Because services and resources are always limited, people with special needs have to be integrated into generic services and

TOO OFTEN USERS FROM CLDB COMMUNITIES FIND THEMSELVES MARGINALISED FROM THEIR OWN CULTURAL GROUP AND COMMUNITY BY VIRTUE OF THEIR DRUG USE.

programs. Even when you try to develop and implement services that are inclusive of people from CLDB, the needs of the wider community can sometimes be the priority due to greater demand, which often overrides the needs of the smaller group. One possible answer to this issue is to develop and implement services along socio-cultural lines whenever appropriate and possible. This, as I said before, is not something easy to do. Working with cultural diversity, in a society dominated by a strong monoculture (Anglo-Saxon) is very difficult. Adding to this all the issues that come with being a drug user, it seems to make this group with specific needs even harder to access.

At the National and State levels, prevention of HIV/AIDS, hepatitis C, STD and other communicable diseases remains the highest priority for the D&A sector, and education and prevention programs for people that inject drugs illicitly will continue to be a high priority of Commonwealth and State governments. However, we still have not seen a coordinated effort to develop and implement services that acknowledge

the fact that for certain groups within our community, mainstream and generic services are not the most effective way to access and serve CLDB communities.

As difficult as it is to access people from CLDB, we should keep upmost in our minds that all people no matter what their background, culture, language or whether they are a drug user or blood borne virus positive deserve equal access to good quality health services, information and

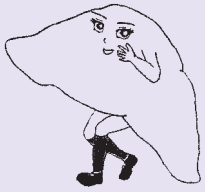
education. This is a responsibility of all of us, and not just the responsibility of ethno or culturally specific services.

At VIVAIDS, we are currently involved in the process of developing resources that will enable people from CLDB to use their own community members as harm reduction agents. Through the translation of our resources to relevant community languages, we are attempting to work together with ethno and culturally specific services on the development of new and innovative ways to access and work with CLDB drug users and their communities.

Cristian Becerra
Harm Reduction Peer Education Officer
VIVAIDS
Telephone: 03) 9419 3633
Email: vivאים@vivאים.org.au

References

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HEPATITIS C AND EXERCISE

**WE ARE RECRUITING HEP C POSITIVE PEOPLE FOR A STUDY
LOOKING AT THE EFFECTS OF MODERATE EXERCISE.**

*THIS STUDY OFFERS PEOPLE WHO HAVE TESTED POSITIVE FOR HEPATITIS C
VIRUS AND DON'T SMOKE THE OPPORTUNITY TO GET FIT WHILE UNDER THE GUIDANCE OF AN EXERCISE
PHYSIOLOGIST (DR GLENN MCCONELL, MONASH UNIVERSITY) AND A LIVER SPECIALIST (DR STUART
ROBERTS, ALFRED HOSPITAL). ALL PARTICIPANTS WILL HAVE THEIR VIRAL LOAD,
LIVER FUNCTION AND FITNESS LEVELS ASSESSED THROUGHOUT THE STUDY.*

*SOME EARLIER STUDIES HAVE EXAMINED THE EFFECT OF EXERCISE ON HEPATITIS A AND B BUT
THIS IS THE FIRST TO LOOK AT HEPATITIS C AND EXERCISE.*

IF YOU'RE INTERESTED OR WOULD LIKE TO FIND OUT MORE PLEASE CONTACT

HELEN GARDINER 0422 136 727 OR JO MITCHELL 9276 2233



STUDY VOLUNTEERS NEEDED

A study on consumer perceptions of "generic" or "cheaper version" of medicines is currently being carried out by a group of pharmacy researchers from Victorian College of Pharmacy, Monash University, Parkville Campus.

This study will involve face to face interview with those consumers who are interested. For your information this study had been approved by Monash University's Standing Committee on Ethics in Research Involving Humans (SCERH).

If you're interested to share you thoughts please contact
Mr Azmi Hassali at :03) 9350 4154, 9903 9057 or 0422 794 688
e-mail: azmi.ahmad.hassali@vcp.monash.edu

The inclusion criteria for this study are:

1. You must be 18 years or above
2. Are currently taking or have taken any form of prescription medications.

"YOUR OPINIONS ARE VERY IMPORTANT FOR US"

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