

AUSTRALIAN HEPATITIS CHRONICLE

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A RESOURCE OF HEPATITIS AUSTRALIA



STATEMENT OF POLICY

The Australian Hepatitis Chronicle is a publication of the Hepatitis Australia National Hepatitis C Program. Hepatitis Australia is a national peak organisation with its membership comprising state/territory based Hepatitis C Councils.

The objectives of Hepatitis Australia are to:

- ▶ Represent at a national level those affected by chronic viral hepatitis and coordinate a national community based response.
- ▶ Contribute to the development and implementation of national policies on chronic viral hepatitis.
- ▶ Promote awareness of chronic viral hepatitis at a national level.
- ▶ Contribute to a national focus for care, treatment and support, and prevention education programs in line with relevant national policies and procedures.
- ▶ Develop and coordinate community based national projects.
- ▶ Assist member organisations by providing a national network/link for education and training resources and coordinate the dissemination of State and Territory produced resources.

- ▶ Address discrimination and promote equitable provision of comprehensive services for people affected by chronic viral hepatitis.
- ▶ Represent its members at national and international forums.
- ▶ Promote medical, scientific and social research into chronic viral hepatitis.

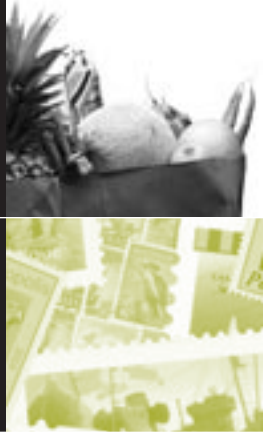
The Chronicle invites contributions from members and non-members who wish to contribute to the Council's goals and objectives.

CORRESPONDENCE

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The closing date for receipt of contributions is 6 weeks prior to publication.



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ACKNOWLEDGMENTS

Thank you to all our members for their continuing action and support.

Thank you to all contributors who submitted material for this 17th issue of the Chronicle.

The Australian Hepatitis Chronicle is a resource of Hepatitis Australia. The views expressed in the Chronicle are not necessarily those of Hepatitis Australia.

SUBSCRIPTIONS

The Chronicle is distributed free to members and others on request.

Requests for bulk copies may incur a postage and handling fee.

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FROM THE EDITOR

John Ratchford, *National Media and Communications Officer, Hepatitis Australia*

Welcome to the 17th edition of the Australian Hepatitis Chronicle. The focus of this edition is personal perspectives, and I would like to thank our contributors for generously sharing their personal stories and experiences.

Often in exploring the myriad social and political issues surrounding hepatitis B and hepatitis C, it can be easy to forget that at the heart of it, living with hepatitis B and hepatitis C is a deeply personal issue.

In this issue you'll find personal perspectives on hepatitis C and injecting drug use, a personal perspective on delivering hepatitis C

training to the NSP sector and a personal perspective on hepatitis and the multicultural community.

We also feature articles about treatment and hepatitis, and a contribution from Professor Geoff Farrell outlining his personal perspective on a life dedicated to hepatology and hepatitis research.

In her guest editorial Skye Wisbey (Projects and Policy officer for Hepatitis Australia) discusses the value of discussing personal stories and the importance of Hepatitis Australia's own Community Reference Group.

Next Issue:

The next issue of the Chronicle will celebrate ten years since the inception of the Australian Hepatitis Council (now Hepatitis Australia) and will include articles and memories from many of the key people involved in the development of the peak national hepatitis body.

Contributions to the Chronicle are always welcomed, and can be submitted to john@hepatitisaustralia.com. Contributors can remain anonymous however we request that contact details be provided to the Editor, who will ensure these details remain confidential.

GUEST EDITORIAL

Skye Wisbey, *Projects and Policy officer, Hepatitis Australia*

THE IMPORTANCE OF PERSONAL STORIES

The sharing of personal stories is powerful - they help us see things from another's perspective, to connect with them for just a moment, and be part of their story. Personal stories tap into that element of curiosity we have about other people's lives and encourage us to learn about things we may otherwise not have found interesting. Depending on the story,

they can provide comfort, inspire and motivate.

The sharing of stories is also profoundly political - whose stories we are willing to listen to affects who has a voice.

Last year Hepatitis Australia established a Community Reference Group as one mechanism for hearing more perspectives from people living with hepatitis C and ensuring these

shape the work we do and the way we do it.

The group of around 20 individuals share their perspectives via email on a range of advocacy, policy and practice issues. The Community Reference Group is only one of the mechanisms Hepatitis Australia employs to not only learn from, but to also be guided by. It's certainly not a flawless method but it makes a statement about our politics and whose voices we want heard.

HEPATITIS C AND INJECTING DRUG USE

Chrissy Ryan, *Hepatitis C Resource Officer - WASUA*

I have been working as the hepatitis C resource project officer at WA Substance User's Association (WASUA) for the past 6 months, and have been involved with WASUA and hepatitis C education and treatment for many years. Apart from being a peer, I believe there are not enough peer support positions in the area of hepatitis C health.

As peers, and people holding paid and credible positions, we are able to promote safe using and educate intravenous drug users in areas where non-peers may not be able to reach or hold sufficient credence to effect change in people's behaviour.

At WASUA we have a needle and exchange program open seven days a week. Through my involvement I speak to many clients who are living with hepatitis C, or who have had hepatitis C in the past. Recently I am finding more and more people who were originally diagnosed with hepatitis C many years ago, and were

later told between 3 - 10 years ago that they had cleared the virus.

Now, these people are being told that their hepatitis C is active again. Some of these people are not sure whether they had a PCR (Polymerase Chain Reaction) test in the past when they were told they had cleared it. The PCR test shows whether the hepatitis C virus is present/active. Perhaps they were told they had cleared it because they had normal liver function tests, which is often mistakenly assumed as a sign of viral inactivity.

I would like to get to the bottom of this matter. Are these people being re-infected, or is the PCR testing more sensitive? I believe this is not the case.

If people are getting re-infected, why is this occurring? Many of these people are regular users of the NSEP service and are asking me how they could be active again after many years of believing otherwise, and all that remained was the antibody.

It is also recommended that everyone should have 2 PCR tests that are both negative over a 6 month period to be classified as having 'cleared the virus'. If anyone has any light they can shed on this matter, please contact me.

Some of the clients have been asking about the risk of being reinfected through using homebake (which is supplied by someone else already to go in the syringe). As with many of these clients, they do not believe that they have been sharing equipment, and are uncertain themselves as to why this has occurred. I am about to start documenting these cases, and would welcome input from anyone who has had the same experience or has relevant information.

On a different note, I am also a fully qualified naturopath. In this capacity, I have worked for seven years treating people with chronic hepatitis C or B and other liver complaints. I am very interested in finding out what sort of results people have had using herbal and natural therapies in the management of their hepatitis C, or

other health issues they may have had related to their drug use.

I have used a combination of antiviral and immune stimulant/balancing herbs, along with liver herbs and whatever may relate to the individual person's requirements with varying results. Almost 100% of clients who take their herbs and supplements

Over 75% of those I have treated have either cleared the virus or had their ALT return to normal range. This is an area I am keen to work more in, as it can be used to support people undergoing medical treatment. I feel it helps them cope with side effects, and makes the treatment more effective.

Natural therapy is also an option for those people who have not had a successful outcome from the medical treatment they underwent, or who found that they prefer to use natural therapies to manage their hepatitis.

Unfortunately, the herbal and natural treatments are not free or subsidised, except at some of the

Almost 100% of clients who take their herbs and supplements regularly and make some changes to lifestyle ... do improve.

regularly and make some changes to lifestyle such as drinking more water, including more fresh fruit, vegetables and wholesome foods in their diet, and getting adequate rest, do improve. By improvement, I am referring to not just how well the client is feeling, but also an improvement in their LFT's (Liver Function Tests).

Nowadays, almost anyone can go on government subsidised (pegylated) interferon and ribavirin treatment, but several years ago this was not the case. People who were not eligible for medical treatment may have considered natural therapies.

hepatitis councils. Some of the liver herbs and supplements are available at cost price, or a discounted rate. Consultations with a naturopath are covered if you have private health cover with amenities or extra cover.

I welcome suggestions, queries or information relating to these matters. I hope that I may assist in improving the quality of life for people living with hepatitis C. My wish is that they can live better, or at least as well as people who do not have hepatitis C.



DELIVERING HEPATITIS C TRAINING TO THE NSP SECTOR

Brad Pierce, *Anex Training Coordinator*

Needle and Syringe Programs (NSPs) have a long history of engaging people who inject drugs on health related matters, and hepatitis C has been at the forefront of these discussions for a number of years.

From a workforce development perspective, it is crucial for the sector to remain up to date with current research and to incorporate this information into their delivery of services.

Whilst this can be challenging for staff within primary funded NSPs, it is often an especially daunting issue for many staff in the unfunded secondary setting. These secondary NSPs comprise approximately 90% of all NSPs, where injecting drug use is not necessarily associated with their primary role of employment.

Participation in training is one avenue that workers have to ensure their skill, knowledge and understanding is congruent with best practice. Finding the time to attend training

can be very difficult for many staff in community service and health organisations. Therefore any training endeavours must be concise, targeted and fulfil organisational requirements to increase staff knowledge and confidence. With this said, there are however, a number of factors that must be considered when developing and delivering hepatitis C training to new NSP workers.

One of the primary considerations must be in relation to addressing pre-conceived ideas about people who inject drugs, and a misunderstanding of the role NSPs play in the public health arena. Staff may unconsciously harbour negative views of illicit drug users, their actions and their health needs, and may therefore be reluctant to engage more positively with service users.

However when invited to critically reflect on their interactions, the

majority of staff involved in NSPs confirm that their service users rarely exhibit difficult behaviours. In fact many training participants identify that people who access the service are very polite and appreciative of positive interactions in the often public and rushed health services environment.

Another key to engaging staff on the topic is acknowledging busy



workloads and understanding that NSP may only be a small part of their work, sometimes as small as monthly involvement in a duty roster system or covering lunch breaks. This is a useful training strategy that improves staff receptiveness, and facilitates an environment where participants are able to discuss their concerns and develop work practices that create opportunities to build positive rapport with people who access their NSP.

alarming trends and the national context of hepatitis C transmission and incidence.

Key topic areas to highlight with new NSP workers include modes of transmission, disease incidence across the population, testing procedures and treatment options. This information provides a context for the topic, and assists workers to develop knowledge and practical

In summarising the complexities in delivering training to NSP workers, it is important to note that training only raises awareness of some of the key issues. It represents a first step in developing skills and knowledge to improve responses to service users. It is essential that staff are provided with opportunities to extend this understanding, and continue to remain up to date in developments in the provision of health interventions.

One of the primary considerations must be in relation to addressing pre-conceived ideas about people who inject drugs.

Providing the evidence in support of NSPs as an effective measure to prevent and reduce drug related harm is also a valuable tool to encourage discussion and understanding. The *Return on Investment in Needle and Syringe Programs in Australia* report¹ is a useful resource in highlighting the positive impact of NSP provision in relation to the transmission of blood borne viruses. I recommend the National Centre in HIV Epidemiology and Clinical Research² data as being valuable for learning about the

strategies that they may utilise within their work with service users.

Discussing the minute amount of infected blood being enough to facilitate transmission, incidence rates among indigenous peoples, issues regarding testing, or accessing the relevant hepatitis council to speak with the experts, are all important areas that encourage participants to be attentive to the health needs of those significantly marginalised from the health care system.

The training environment can also provide access to resources and links to state hepatitis councils, user organisations, local AOD services or general practitioners to encourage and support the staff and wider organisation to establish collaborative work practices. Whilst collaborative endeavours can be time and resource intensive, the benefit of more positive outcomes for service users makes it very worthwhile.

¹ Health Outcomes International (2002). *Return on Investment in Needle and Syringe Programs in Australia*. Commonwealth Department of Health and Aging, Canberra

² Ministerial Advisory Committee on AIDS, Sexual health & Hepatitis: Hepatitis C Sub Committee. *Estimates and Projections of the Hepatitis C Virus Epidemic in Australia 2006*

45 AND STILL ALIVE

Danny Gallant

This was the unofficial theme of my recent birthday celebration, so happy just to be alive. It was a chance to celebrate the passing of the biggest year of my life. In the early hours of August 26, 2006, as I lay very sick in a hospital bed, I was given the news that I was just hours away from receiving a donated liver.

Twenty years ago no one would have believed it possible.

My journey to transplantation really began in 1986, when I presented to a sexual health clinic to enquire about receiving a vaccine for hepatitis B. I consented to a battery of tests for a complete sexual health screen, including a test for HIV.

Soon afterward I was contacted by the clinic and asked to come in for the results. What I was told would change my life forever. I was not a candidate for the vaccine because I was already chronically infected with the hepatitis B virus. If that wasn't

devastating enough, I was also told I was co-infected with HIV.

In the ensuing months I was told by that my liver was cirrhotic and my immune system was severely compromised. When finally I mustered the courage to ask about my life expectancy, I was told that if HIV didn't kill me within two years, the hepatitis B would within ten. In case that wasn't enough to cope with, the consultant thought it important that I knew then that I was not a suitable candidate for liver transplantation. No matter how many

second opinions I sought, the story was the same.

Those were the bad old days when HIV was just starting to declare itself, and there was widespread public fear and panic. I witnessed too many friends and my dear uncle die with painful and disfiguring lesions, emaciated and unable to breathe or swallow. In response to HIV, there were ideas mooted at high levels about limiting civil liberties and quarantine measures in the interest of public health.

Through the heroic and benevolent act of a total stranger, I was given the gift of life.



These were desperate times for many of us. For my close friend Jim, it was too hard to navigate through, so he took his own life before his pneumonia and Kaposi sarcoma could. I still cannot fully articulate the trauma of that time this many years later.

Despite everything I did manage to survive, and with the introduction of highly active anti-retroviral therapy (HAART) my immune system vastly improved, and the HIV virus became undetectable. I fought hard for compassionate access to Interferon to treat the hepatitis B, but in the end this treatment failed to eradicate the virus.

When Lamivudine was added to my HAART regime, I was given the news that the hepatitis B in my system was also suppressed. Finally my health seemed to stabilise, and I remember ushering in the New Millennium feeling hopeful for the first time in over a decade.

It was generally accepted that chronic HIV could be a manageable illness, but I remained wary of hepatitis B lurking in the background. Over the years the cirrhosis led to chronically elevated liver function tests, abnormal bleeding times, low platelets and portal hypertension. Along with my doctors I wondered how long this could go on before it would all start to go wrong.

The answer came in a very dramatic way when I had a gastrointestinal bleed in November 2005 from a large varix caused by portal hypertension from cirrhosis. The treating gastroenterologist told me that the horse had bolted. In other words, I could expect it all to go downhill from here.

By this time HIV was no longer a contra-indication for transplantation. Without hesitation I requested to be assessed for a liver transplant, but was told there was perhaps five, ten or even twenty years before that last

resort option was needed.

However, within eight months I was admitted to hospital for a week long transplant assessment. I had rapidly gone into liver failure and encephalopathy took hold. By the end of that week of investigations I was put on the waiting list for a liver transplant, but there was little hope given to me because of how advanced the liver disease was. There were many dark moments before suddenly the news came exactly one week later that a donor match had been found.

It was the most profoundly moving moment of my life on so many levels, not the least of which was accepting that my continued life was linked to another person's death. Through the heroic and benevolent act of a total stranger, I was given the gift of life. Almost eight months later, not a day goes by that I do not in some way honour this person's life.

HEPATITIS AND THE MULTICULTURAL COMMUNITY

Enaam Oudih

A mother wearing gloves every time she handles her new born baby because she is scared of infection.

A woman who avoids buses - scared of getting the disease.

A man divorcing his wife because she told him of her diagnosis.

backgrounds', says Adelaide-based P.E.A.C.E manager Enaam Oudih.

'CALD people are diverse in many ways - through their religion, country of origin, language, personal experiences, their reason for migration, their journey of migration, their experience of settlement - and all of these experiences influence the

'When CALD people hear the word hepatitis, it doesn't matter what letter is attached to the end of it: A, B or C. They assume that hepatitis is hepatitis and that the one being discussed is the one relevant to them. This gets even more complicated when we need to address non-viral and viral hepatitis,' says Enaam.

'I need to be genuinely curious about people's life context and tailor interventions and strategies so that they become meaningful for them...'

Far-fetched examples of people's reaction to Hepatitis? Not for P.E.A.C.E (Personal Education & Community Empowerment) Multicultural Services, part of Relationships Australia (SA).

'These are scenarios we have faced in working with people from culturally and linguistically diverse (CALD)

way people interpret or make sense out of the virus and the diagnosis'.

CONFUSION ABOUT HEPATITIS

Like the community at large, confusion about the different types of hepatitis is widespread in the non-English speaking community.

The confusion influences the preventative measures that people take, sometimes adversely. Such as the wearing of gloves, which is appropriate for hepatitis A, but not C.

'Another example is a women who identified that she had hepatitis C and sought help for it. But when information was given to her, she

asked why she had not been offered immunisation when later it was discovered that she actually had hepatitis B.

'When service providers explain that hepatitis C is an infectious disease, CALD clients automatically view the situation within their own cultural context and interpretation of what "infectious" means to them', says Enaam.

'Therefore we as service providers must pay attention to our language and CALD client's potential interpretations'.

'SHARED MEANINGS'

Service providers need certain skills when dealing with people who speak little or no English, such as the use of interpreters and the development of appropriate resources.

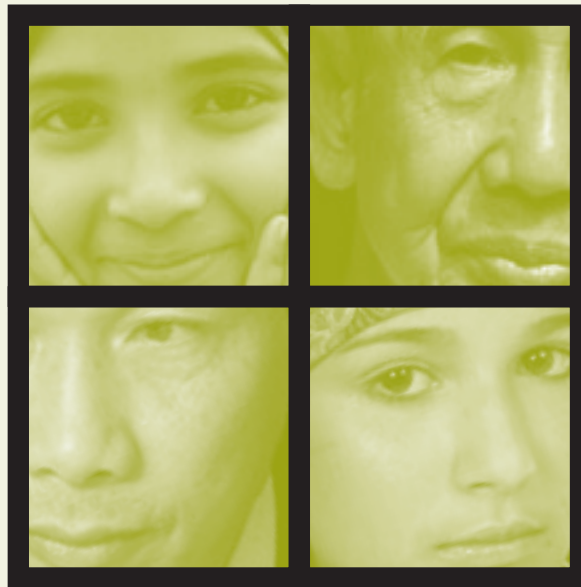
'Can you be surprised when a client did not consent for a biopsy because the interpreter explained it meant "cutting a piece of the liver"?' asks Enaam.

'It is the responsibility of the service provider to ensure that clients are appropriately informed. And it is never as simple as just booking an interpreter - it is a lot more complex than that. It is about the language,

religious, and cultural interpretation'.

She recommends instead that the service provider try to work with the client for a shared meaning and understanding of the disease.

'The interaction between service provider and newly diagnosed person



must be a two-way communication. Only then can we work on incorrect perceptions or assumptions to find relevant and familiar strategies for dealing with infection'.

'CHALLENGING BUT REWARDING'

Enaam, who is Palestinian herself,

reveals a passion about the development of useful resources for CALD clients.

'I must admit that I am a bit apprehensive, because it can be tokenistic, especially if it is used as a stand alone strategy. I have met so many clients that read written materials in total isolation from their life context. And what about the illiterate? And what happened to building social fabric as opposed to building piles of translated material that hardly gets used? Development of any resource needs to be community driven - it needs to be appropriate and addresses their needs. We just need to trust them more and work in partnership with them'.

'Working with CALD people is very challenging, but at the same time is very rewarding.' Enaam confides.

'I need to be genuinely curious about people's life context and tailor interventions and strategies so that they become meaningful for them. For me it is not about getting it right all the time, it is about the ability to recover from the mistakes I make. That is what cross cultural work means to me'.

PERSONAL PERSPECTIVES

Professor Geoff Farrell

In the 1950's I suffered from hepatitis A - I was 9 years old, but some memories linger. The scary delirium at onset, isolation from family members and friends, the profound weakness (after 6 weeks in bed!), and feelings of alienation when I was allowed, at last, to return to school.

I do not know whether this experience motivated my choice of medicine as a career, but I vividly recall seeing my first yellow patient (from jaundice) as a medical student, a young woman with hepatitis. My fascination and empathy with this patient, together with the inspiration of learning around the same time (circa 1968) that the hepatitis B virus had been identified, paving the way for the first vaccine to prevent hepatitis, influenced a subsequent decision to specialise in liver disease (hepatology). Looking back from where we are now, how little we knew when I graduated from the University of Tasmania Medical School in 1970! This gives me pause to wonder why

I chose this path, but not for one moment have I regretted it!

Two other "events" during my training influenced my thinking on the social and moral dimensions of hepatitis.

A junior registrar at a now-closed Sydney district hospital, I was asked to assess a jaundiced lady in Cas. She too had hepatitis A, but was recovering and did not need admission. None-the-less, I wanted to see her again to reassure her and myself that she was on the road to complete recovery. Imagine my dismay (and hers!) to be instructed that this could only be done (because the patient "was infectious") in a remote, isolated small room in a dingy attic. Fear, ignorance, and discrimination have surrounded viral hepatitis in Australia from way back, and later found ready re-emergence with hep C!

A few months later, I was in PNG, and it was a common and confronting experience to admit young men with liver cancer, all due to hep B. A devastating disease to witness,

let alone suffer, but one that can now to be combated by community application of hepatitis B vaccination, as developed in 1982, and for those already infected, with the successful antiviral therapy that has emerged during the last 10 years.

In 1980, my training and formative years completed, I returned from post-doctoral research in San Francisco (on esoteric biochemical studies of liver enzymes!) to start the liver unit at Westmead Hospital in western Sydney. Since 1993, this unit has been known as the Robert W Storr Liver Unit in honour of the generous man who endowed the bequest that carries his name. Robert Storr sadly died of liver cancer, and his vision was to improve public awareness about the risks of this disorder.

During the mid-1980s, we became aware that a large number of patients with "hepatitis" in our liver clinic had neither hep A (which is never chronic) nor hep B. With the discovery of the hepatitis C virus (HCV) in 1989, we were able to

...the establishment of the Hepatitis C Council of NSW, in the first instance by patients under my own care... remains one of my most satisfying “achievements”.

show that all such “non-A, non-B hepatitis” cases were due to HCV. We had gained experience with treating hepatitis B with interferon, and before long this become the mainstay of antiviral therapy for hepatitis C, the first Australian trial coming from Westmead.

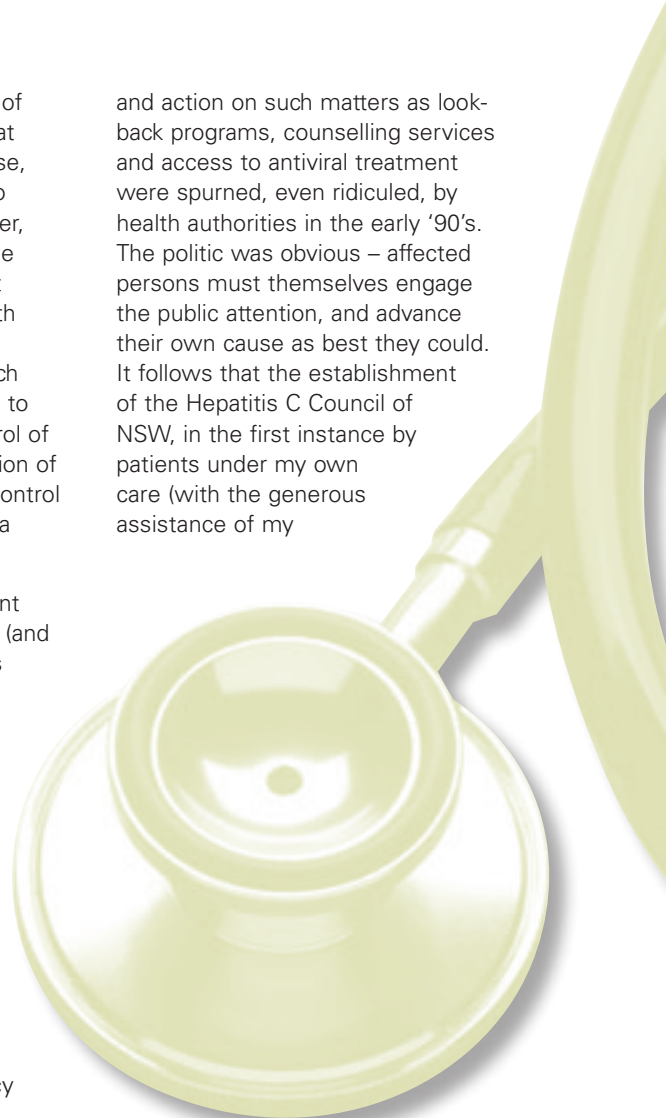
Advances in knowledge about common diseases now often occur at a startling pace, and one of the great privileges of my career has been to participate in hepatitis C research. The treatment that was so marginally effective in 1990 (6 months of interferon, 10-25% cure) has been improved by addition of ribavirin, development of long-acting (pegylated) interferons, and individualisation of treatment course, particularly lengthening it to 1 year for genotype 1 and 4 HCV infections. We can now cure up to 90% of people infected with HCV genotypes 2 or 3, and 40-50% of those with genotypes 1 or 4.

Even more impressive is the development of support services, particularly specialist nurses, psychological services and patient support groups, all of which play crucial roles in getting people through

what remains an arduous form of therapy. We have also learnt that hep C is a highly variable disease, with only a minority going on to develop cirrhosis and liver cancer, and we have much more reliable information to predict who is at risk of these complications. With all affected people, irrespective of severity of liver disease, much emphasis has, rightly, switched to improvement of health by control of dependent behaviours, prevention of further infections, and weight control by regular physical activity and a balanced “heart healthy” diet.

More importantly, we have learnt that the barriers to good health (and happiness) for affected persons are broad: they include social prejudice, discrimination, impaired quality of life in both psychological and physical dimensions, and the implications that all these things have for relationships and well-being. The “medical role” is rather limited in countering these challenges for people with HCV; indeed, my own attempts to stimulate the development of public policy

and action on such matters as look-back programs, counselling services and access to antiviral treatment were spurned, even ridiculed, by health authorities in the early '90's. The politic was obvious – affected persons must themselves engage the public attention, and advance their own cause as best they could. It follows that the establishment of the Hepatitis C Council of NSW, in the first instance by patients under my own care (with the generous assistance of my



I am grateful to learn that the people who are “my failures” still intrust me with their care, and are most often forgiving and extremely grateful...

personal secretary, Diane West), remains one of my most satisfying “achievements”

The many highs (and privileges) of an academic career in medicine include the association with bright young students and doctors in training, the discovery of new knowledge about disease processes that leads to improved management or prevention of disease complications, and the “technology transfer” of new

modalities of treatment into the clinic, so benefiting the patients who have trust in their specialist. My career has recently received a new lease of life in Canberra and the new ANU Medical School. Meanwhile, some of my most humbling experiences, the acceptance of failure counter-balanced by hope, human dignity and gratitude are among the most cherished. Painfully aware of the limitations of medical treatments and the ability to prevent all possible bad outcomes, I am grateful to learn that the people who are “my failures” still intrust me with their care, and are most often forgiving and extremely grateful for my attempts to convey understanding to them, and for ameliorating their distress.

My own mentor professor taught me to never neglect the dying patient, to spend time talking with them and their families rather than abandoning “hopeless cases”

I hope to pass on to my students similar dimensions of caring, now blended with the growing potency of scientific medicine so that hope and alleviation of suffering can be effectively accomplished more often. The first dictum in my clinic is: *what have I done (no matter how small) to improve this patient's care? The second is: did that person leave the room feeling better than when they entered - better still: were there laughter and smiles?*

Professor Geoff Farrell MD, FRACP is Director of Gastroenterology and Hepatology at The Canberra Hospital, and Professor of Hepatic Medicine at the Australian National University Medical School. He has been the Patron of the Hepatitis C Council of NSW since its inception in 1991. In 2003, he received the Distinguished Research Prize from the Gastroenterological Society of Australia. He has published three books, written more than 250 articles, reviews and chapters in the fields of hepatology and hepatitis research.

PERSONAL PERSPECTIVES

Valdis, *Positive Speaker*, Hepatitis C Council of SA

I am a fifty year old male with tattoos, pierced ears and a history of intravenous drug use. When I was diagnosed with chronic hepatitis C in mid 2003, I was faced with the dilemma of having treatment or not. Apparently I had been infected with the virus for at least a decade, maybe even two, but I had not displayed any obvious symptoms. My lifestyle and general health had not been disrupted.



Having been previously diagnosed and treated successfully for hepatitis B in 1979, I had no hesitancy in accepting treatment for hepatitis C. The treatment for hepatitis B was quite simple: a shot, some tablets, a low fat diet, lots of fluids and abstinence from alcohol while I was quarantined for a week. It was as easy as getting rid of a dose of the 'clap'.

To my dismay, I had to give up drinking again which required much willpower as well as counselling. A liver biopsy was also performed. To the relief of many people, this procedure is no longer mandatory. After six months of alcohol abstinence and the determination of my hepatitis genotype, I was ready for the treatment programme.

Before starting treatment I was provided with information regarding side-effects and was told that I might endure side-effects not even listed. Hair loss and depression were



two of the featured side-effects I recall reading about, but I found that my hair growth improved and that any depression I felt was due to the alcohol abstinence.

The dominant side-effects for me were weight loss, nose bleeds and a sleeping disorder. When I experienced nausea for a short time, the clinical nurse suggested I drink ginger beer or ginger ale, and perhaps even supplement my meals with ginger. This worked perfectly and I am grateful to the clinical nurse for her advice. (Thank you Robin!)

So for twenty four weeks I was self-injecting interferon once a week and taking ribavirin tablets twice a day. At times I would be very irritable, and I was not a very social being. I found it necessary to focus on something, something to occupy my mind and the time. The first three months of my ordeal I spent cataloguing my stamp collection, and then I enrolled in a Russian language class.

During this period I saw a counsellor about once a month. To be able to

and also returned to an active social life. I am also now an active positive speaker with the Hepatitis C Council of SA.

In the last three years I have met several people who have had treatment and we've shared a few of the same experiences. I've also met people who are still undecided about beginning treatment.

I do not regret enduring the treatment. In fact, if I had been

At times I would be very irritable, and I was not a very social being. I found it necessary to focus on something, something to occupy my mind and the time.

disclose to someone how I was feeling helped to alleviate some of the stigma attached to having hepatitis C.

At the end of my treatment I was very much relieved when I was told that I had cleared the virus. After treatment I immediately began to put on weight again, the nose bleeds stopped and my sleep returned to a regular pattern. I enrolled in a mathematics subject at University

diagnosed earlier my body might be a lot healthier than it is now.

I would like to extend my gratitude to the Flinders Medical Centre, to my counsellor and to all those who gave me support during my 'ordeal'. To all those people contemplating treatment, I wish you strength. And remember, it may make you a better person.



NEWS & RESEARCH

NATIONAL HEPATITIS C PROMOTION AWARDS

Hepatitis Australia is proud to announce the recipients of the inaugural National Hepatitis C Health Promotion Awards.

Two awards were presented in recognition of excellence in hepatitis C education, prevention, information provision and support.

The Excellence in Hepatitis C Health Promotion Award was presented to the Picnics in the Park in recognition of project excellence. This project is a partnership between

Hepatitis Council of Queensland, Queensland Injectors Health Network (QuIHN) and Brisbane Youth Service.

The Outstanding Service to the Hepatitis C Sector was presented to Paul Harvey of the Hepatitis C Council of NSW in recognition of outstanding individual service.

Hepatitis Australia would like to thank all those who nominated projects or individuals for these Awards and acknowledge the exceptional quality of all nominated projects and commitment of all individuals nominated.

The awards were judged by a panel of three judges with long standing involvement in the hepatitis C sector.

The Awards were announced at the National Hepatitis C Health Promotion Conference on the 5 June, 2007 by Hepatitis Australia's CEO, Helen Tyrrell.

A full wrap up of the conference will be appearing in a future edition of the Chronicle.

THE PROFESSOR GEOFF FARRELL MEDAL

The Professor Geoff Farrell Medal Recognising Excellence in Hepatitis C Reporting was launched Thursday April 19 at the 5th World Conference of Science Journalists, Melbourne Grand Hyatt.

The award honours Australian-based members of the media who have provided responsible, accurate and timely reporting on advances in hepatitis C prevention, research, treatment and patient support.

A mixture of twenty-three Australian and International Journalists including Dr. Janet Salisbury, Director of Biotext, Dr. Gareth Forde, Chemical Engineering Lecturer at University of Monash and Rada Rouse of Medical Observer Weekly attended the launch, and heard talks from Hepatitis Australia President Helen McNeill and Associate Professor Margaret Hellard.

Helen McNeill spoke about the award and how responsible journalism can help to combat discrimination and stigma around hepatitis C issues. Margaret Hellard spoke about the global and Australian approach to the management of the hepatitis C epidemic, and also discussed some of the difficulties people with hepatitis C face in seeking and continuing treatment.

A Question and Answer chaired by President of the Australasian Medical Writers Association Tina Allen session was held afterwards, with the journalists present posing a variety of questions including questions about hepatitis C and contaminated water, vaccination, tattooing and administration of hepatitis C treatment in Australia.

All journalists present were supplied with copies of the Hepatitis Australia Estimates and Projections Factsheet, the Hepatitis C in Australia factsheet, our guide to correct media terminology and nomination forms for the award itself.

For a copy of the nomination form see www.hepatitisaustralia.com

MEDIA RELEASES

Please see www.hepatitisaustralia.com for a comprehensive list of all recent media releases.



CONTACTS

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STATE/TERRITORY COUNCILS

The state and territory councils are members of the Australian Hepatitis Council.

ACT Hepatitis C Council

Tel: 02 6257 2911
Fax: 02 6257 1611
Helpline: 1300 301 383
www.acthepc.org
Executive Officer:
Robyn Davis
Email: info@acthepc.org

Hepatitis C Council of NSW

Tel: 02 9332 1853
Fax: 02 9332 1730
Helpline: 9332 1599 (Sydney callers)
1800 803 990 (NSW country callers)
www.hepatitisc.org.au
Executive Officer:
Stuart Loveday
sloveday@hepatitisc.org.au

Hepatitis Council of QLD

Tel: 07 3236 0610
Fax: 07 3236 0614
Helpline: 07 3236 0612 (metro callers)
1800 648 491 (QLD country callers)
www.hepqld.asn.au
Chief Executive Officer:
Clint Ferndale
ceo@hepqld.asn.au

Hepatitis C Council of SA

Tel: 08 8362 8443
Toll Free: 1800 437 222 (SA country callers)
Fax: 08 8362 8559
www.hepccouncilsa.asn.au
Kerry Paterson
kerry@hepccouncilsa.asn.au

Hepatitis C Council of Victoria

Tel: 03 9380 4644
Toll Free: 1800 703 003
Fax: 03 9380 4688
www.hepcvic.org.au
Executive Officer:
Helen McNeill
helen@hepcvic.org.au

Hepatitis Council of WA

Tel: 08 9227 9800
Fax: 08 9227 6545
Helpline: 08 9227 8538 (Perth callers)
1800 800 070 (WA country callers)
www.hepatitiswa.com.au

Manager:

Frank Farmer
manager@hepatitiswa.com.au

NT AIDS and Hepatitis Council

Executive Director:
Colin Burden
cburden@ntahc.org.au

Darwin office

Tel: 08 8941 1711
Fax: 08 8941 2590
www.ntahc.org.au

Alice Springs office

Regional Manager:
Jill Meade
jmeade@ntahc.org.au
Tel: 08 8953 3172
Fax: 08 8953 2925
www.ntahc.org.au

Tasmanian Council on AIDS Hepatitis and Related Diseases (TASCAHRD)

Tel: 03 6234 1242 (Hobart callers)
1800 005 900 (country callers)
Fax: 03 6234 1630
www.tascahrd.org.au
Executive Officer:
Kevin Marriott
kmarriott@tascahrd.org.au

SERVICE DIRECTORY

National

Australian Hepatitis Council (AHC)

02 6232 4257

www.hepatitisaustralia.com

Australian Injecting and Illicit Drug Users League (AIVL)

02 6279 1600

www.aivl.org.au

Alcohol and other Drugs Council of Australia (ADCA)

02 6281 0686

www.adca.org.au

Haemophilia Foundation of Australia (HFA)

03 9885 7800

www.haemophilia.org.au

National Aboriginal Community Controlled Health Organisation (NACCHO)

02 6248 0644

www.naccho.org.au

National Association for People living with HIV/AIDS (NAPWA)

02 8568 0300

1800 259 666

www.napwa.org.au

Anex

03 9486 6399

www.anex.org.au

Australian Capital Territory

ADIS (Alcohol & Drug Information Service)

1800 198 024

Directions ACT

02 6122 8000

ACT Department of Health and Community Care

02 6207 9977

New South Wales

ADIS (Alcohol & Drug Information Service)

1800 198 024

NSW Department of Health

02 9391 9000

NUAA (Drug User Group)

02 9557 1476

www.nuaa.org.au

TRAIDS (HIV & Hepatitis C Counselling and Information Centre)

02 9843 3143

Northern Territory

ADIS (Alcohol & Drug Information Service)

1800 198 024

Alcohol and Other Drug Services

08 8922 8399

Hepatitis C Hotline

1300 437 222

Dept. Health and Community Services

08 8999 2400

Queensland

ADIS (Alcohol & Drug Information Service)

1800 198 024

Brisbane Youth Services

07 3252 3750

www.brisyouth.org

Cairns Youth Link

07 4031 6179

www.youthlink.org.au

DUNES – Gold Coast (Drug User group)

07 5520 7900

Ethnic Communities Council of Qld

07 3844 9166

**Qld Health Department
(Communicable Diseases Unit)**

07 3234 1155

QuIVAA (Drug User Group)

07 3252 5390

1800 172 076

**SCIVVA – Sunshine Coast
(Drug User Group)**

07 5443 9576

South Australia

**DASSA (Drug and Alcohol Services
South Australia)**

1300 131 340

Hep C Info & Support Line

1300 437 222

Mosaic Counselling Service

08 8223 4566

1800 182 325

**SA Health Commission
(Communicable Diseases unit)**

08 8226 6000

SAVIVE (Drug User Group)

08 8334 1699

1800 888 559

Tasmania

**ADIS (Alcohol & Drug Information
Service)**

1800 811 994

**Community and Health Services
(Sexual Health Branch)**

03 6233 3557

1800 671 738

The Link (Youth Health Service)

03 6231 2927

Victoria

**Directline (Counselling & Referral
Service)**

1800 888 236

Hepatitis C Helpline

1300 437 222

Human Services Department

03 909 6000

1300 650 172

Western Australia

**ADIS (Alcohol & Drug information
Service)**

1800 198 024

WA Department of Health

08 9222 4222

WASUA (Drug User group)

08 9227 7866

