# The Hep C Review

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# Combination therapy approved as standard treatment in USA

**The United States Food & Drug Administration has approved Schering-Plough's Rebetron combination therapy (ribavirin and interferon) for the treatment of chronic hepatitis C in people who have liver disease previously untreated with interferon therapy alone.**

The decision was based on clinical data from two pivotal multicentre studies involving people not previously treated. Results of these studies showed that combination therapy resulted in a significant increase in the number of people showing a sustained loss of detectable HCV compared with those receiving monotherapy (interferon alone).

Six months after therapy was completed, 198 of 496 people (40%) who were treated with 48 weeks of Rebetron combination therapy had undetectable levels of HCV, as compared to 73 of the 491 patients (15%) who were treated with 48 weeks of monotherapy.

This suggested 40% sustained response rate is clearly a great improvement on the initial interferon sustained response rate of 10-15% - seen when interferon was provided by itself for 6 months treatment.

An Australian trial of interferon/ribavirin - called Aushep 8, has recently been initiated (see p38). Part of a larger international research project, we hope that Aushep 8 will provide valuable Australian evidence that supports the combination therapy as a standard treatment for hepatitis C.

Should hard evidence emerge for widespread or targeted usage, we would urge the Commonwealth government to fast-track Pharmaceutical Benefits Scheme listing of the treatment.

- Adapted from a news article taken from the internet email list: HEPV-L

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The Hepatitis C Council is an independent, community-based, non-profit membership organisation. We provide information and support to people affected by hepatitis C and assist in preventing further spread of the hepatitis C virus. We are primarily funded by NSW Health.


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# Optimum complementary healthcare

Our western healthcare system has been firmly based on 'scientific medicine' for 200 years. Comparatively recently, there have emerged a range of 'alternative' healthcare approaches based on fundamentally different notions of treatment - in most cases, hinging on a person's belief in the body's ability to heal itself through achieving balance of fundamental life forces.

It is believed that on an annual basis, one in five Australians make at least one visit to an complementary therapist - mainly including osteopaths, naturopaths, acupuncturists and Traditional Chinese Medicine practitioners - and one half of our population is believed to use at least one non-medically prescribed complementary medicine each year. The associated expenditure on complementary healthcare is believed to be close to $1 billion.

Studies have shown that Australians who utilise complementary therapies report "substantial and persistent improvements in their conditions and high levels of satisfaction with treatment".

Our Western medical profession, based on scientific questioning and technology that can provide insight into the most minute human physiological functions, has as a whole, reacted cautiously to the emerging therapies. Opinions of healthcare workers range from considering complementary therapies as being fraudulent, through to their being useful or harmless.

A random study of approximately one third of general practitioners in Auckland, N.Z., suggests that 30% of GPs practise some form of complementary therapy. It also found that 68% of doctors surveyed would, if necessary, refer patients to complementary therapists. Over 60% of GPs surveyed, though, regarded complementary therapies either negatively or ambivalently, and often referred patients on to therapists in the hope that "something curative or palliative might be achieved, or for psychological benefit".

Whatever opinion individual doctors may have on complementary therapies, it cannot be denied that with the existing large number of qualified complementary therapists, the considerable number of people using their services, the many GPs who undertake training in complementary therapies, and the fact that some health insurance funds now provide coverage for complementary therapies, this field has become an integral part of our healthcare system.

Acknowledging this position, we must ask ourselves, "Have our government and medical professional bodies responded appropriately to complementary therapies?"

Doctors who practise complementary therapies do so in their capacity as an accredited GP, but a very different approach applies to complementary therapists. Only chiropractors and osteopaths are registered in all Australian states and territories.

Well informed consumers may seek out therapists who have undertaken formal training at well-regarded colleges, and who have demonstrated experience in particular therapies.

***"checks and balances must be continually strengthened to ensure that the best interests of patients are served"***

Other people, though, may find themselves being treated by people with little formal training. Indeed, a person with no training whatsoever can set themselves up and practise as a 'natural therapist' - so long as they do not use scheduled drugs or invasive diagnostic or therapeutic procedures, nor cause physical injury.

Currently, there are calls to introduce registration of certain complementary therapists. A review of Traditional Chinese Medicine (TSM) tendered by the Victorian, NSW and Qld governments strongly recommends government registration of TCM practitioners. Some complementary therapy professional bodies call for a continuation and improvement of the existing self-regulation system. Within this system, practitioners go through a rigorous investigation of their training and qualifications prior to accreditation within a professional mebership body (see page 41 for listing of such bodies).

Complementary therapies will most likely evolve alongside our existing western medical model - as 'complementary' therapies - with individual therapies and medicines being adopted following their thorough scientific trialling, as has happened historically (see article, p 12).

But due to the range of existing and emerging complementary therapies, many will remain untrialled and unproven. The Hepatitis C Council of NSW urges complementary therapists to work with researchers towards obtaining government funding to run properly controlled and documented clinical trials of the therapies they promote.

What ever the outcome, checks and balances must be continually strengthened to ensure that the best interests of patients are served. Governments have a major role in ensuring optimum levels of care are maintained.

# To drink or not to drink

The question of alcohol seems to be as long as a piece of string. I suppose we can only make a personal decision on this, with as much information as we can gather to help us.

It is such an emotive subject for people with any type of liver disease. Some of us here have had or are having battles with the addiction of alcohol, some of us are having a hard time accepting our illness and grieving the loss of health and all the other things that go with it, like a glass of wine occasionally. Missing a drink now and then seems (to me) quite normal under these abnormal circumstances we find ourselves in.

We hear so much of the bad side of booze, and of course there is so much to say on the subject. But we do need to be able to affirm some of the positive aspects of alcohol. It does have a large place in society; it is society's most used and abused legal drug. We have been conditioned to consider alcohol to celebrate with, to commiserate with, to relieve shock, to relieve stress, to help us loosen up and enjoy. We also can use it to escape from all the stuff life throws at us and so easily become dependent; it is highly addictive and seductive.

The issue of quality of life is once more, a very personal choice. It can be argued that the stress caused by denial of something pleasurable and in moderation, can be more harmful to the body than the glass of wine. It could be said that some people replace alcohol with tranquilisers and pain killers and the argument could once more be, which causes more harm?

The debate is as long as that piece of string. As always, we must be guided by our doctors and our bodies. My doctors have told me several little gems of advice on alcohol, from being told I could have none, to being told I can have the recommended limits. Go figure! But my body tells me that it no longer can tolerate alcohol, even in the tiniest of amounts. It of course took my 'conditioned head' some time to catch up with the obvious.

I feel that doctors play an important role in diagnosis and assessment. A sensitive approach to case history can make all the difference in the world to a newly diagnosed person's attitude to alcohol.

I always try to help people to accept that it is difficult to change social habits of a lifetime - but in regard to drinking, that does not mean they are alcoholics. It means they are behaving normally under abnormal circumstances.

I wish you peace to make your choices, and would add that in NO WAY, am I advocating or condemning the use of alcohol in any way. Simply sharing my observations.

Hope all are well and with peace. Much love and light

**Feyona**

*Also see articles on alcohol: Ed23, p20; Ed22, p20 - Ed.*

# Far from alone

Hi, just a short note of thanks for the continuing support and information you send me. I really do appreciate it, reading other people's stories, and the articles on diet and other professional information is great. It is very reassuring that I'm far from alone with this crazy, frustrating disease.

I've just come out of hospital with an ulcer, severe pain and chronic cirrhosis. I was vomiting blood and spending untold time on the loo also losing blood.

Plus I'd blown up like a balloon with ascites and was carrying an extra 9.5 kilos of fluid. *[Ascites is an accumulation of fluid within the lining of the abdominal cavity.]*

All in all it was not a very pleasant experience - all in all, a bit of a freakout!

But I'm home now and recovering, taking medication to try and help everything - it's very boring having to pop all those pills.

But I'm happy to say I'm 9.5 kilos lighter, good God! I had looked so weird as I'm only normally a tiny frame.

Unfortunately I've still to find a doctor who understands hep C or should I say, explains it properly. That's why the magazine is of great comfort.

Thanks, anyway. I must get going and am enclosing my membership renewal.

Once again, thanks heaps! Also to all the many other people in the same boat - hang in there and take care.

**Sincerely, Kim**

*Thank you, Kim, for sharing your story with us - Ed.*

# Whata we doin' New Years Eve

I guess I better back up a bit.

I found out I was hep C positive in Nov' 95. It was about seven months before that I'd stopped using drugs thanks to my then girlfriend who I married in March 96 (we have since divorced).

I had also been an alcoholic since about 1984. Being drunk became my full-time hobby although I continued working full-time during all that time, up to a couple of years ago.

That was when I suffered a variceal hemorrhage in the upper stomach and lower esophagus. Trust me, after that I didn't need anyone from AA or counselling from anyone. I haven't had a drink since.

I didn't think things would end up like this. I thought I would just drop dead (I told you I was a stubborn idiot).

My hemorrhage happened close to New Year's Eve so I was still dressed in a hopsital gown thanking doctors, God, and doctors.

But this recent New Year was different. I don't really know anyone out this way. Being with people who are drinking doesn't worry me until they're really pissed - and then that just makes them annoying.

Okay I have an idea. Why can't we somehow organise a New Year's night for others who feel the same way I do?

Obviously there would need to be more than one or two "parties" because of the distances between us all.

I don't know if we can make this work or not, but getting things happening this early is a start.

Anyone with ideas to add or are just keen on the idea should contact the Council.

Man, I miss going into Sydney Town, getting wasted and having a great time. But life ain't over till the fat lady sings.

Let's party New Years!

**BJC**

# Faulty fitpacks

I write to express my concern about the fitpack type sharps disposal containers that are currently widely distributed by the NSW needle & syringe program.

As a nurse & a weekend user, I became very concerned when I discovered the high risk of transmission of the Hep C virus. I always follow safe injecting procedures. I never share equipment, including my torniquet and I always dispose of my equipment safely. My friends and I regularly share a common fitpack with five syringes, as this usually suits our requirements. I did not become aware of the dangers of this until recently.

Syringes are usually provided to us in a fitpack. I have been told by the needle & syringe workers that I should always return the used syringe back into the fitpack. I followed this procedure until yesterday, when I accidentally broke the fitpack.. I discovered that the packaging on my clean syringes was directly adjacent to, and contaminated by the used syringes that I returned to the pack. Call me paranoid, but I will not use fitpacks again.

One of my friends recently tested positive to HCV and I know that they also follow the same "safe" procedures. Having used fits taken from his fitpack, I feel very lucky not to have caught hep C from him.

The level of safety in these packs is supposed to be O.K. for drug users, but working in a hospital, I know this would be unacceptable for hospital patients. I wanted to make other readers aware that there is a potential risk, but also would like to know what else I can do to change this situation for other users who may be unaware of this design fault.

**Worried**

*Dear Worried*

*We have passed on your letter to NSW Health.*

*Two of three fitpacks currently available were checked by the Council and do not have a full seperator wall. We do not have the scientific expertise, though, to determine whether this poses any contamination risk.*

*We hope that relevant experts can determine if this is so.* *Ed.*

# Complementary therapies

"Alternative", "natural", "complementary", "new-age", "holistic" and "eastern". These are terms that have been used to describe a range of different healthcare interventions that have emerged comparatively recently in Australia.

They include more commonly recognised approaches such as Traditional Chinese Medicine (TCM), herbalism, acupuncture, homoeopathy and naturopathy, as well as less common therapies such as crystals, flower remedies, spirit channelling and therapeutic touch.

Research suggests that between 20-30% of Australians may have used at least one complementary therapy within any 12 month period. Also, given that N.Z. studies suggest that up to 30% of GPs practise some form of complementary therapy, these emerging therapies must be of interest and relevance to many of our readers.

This edition of *The Hep C Review* aims to provide information about complementary therapies in order to assist people make decisions about their personal healthcare strategies.

The Council neither promotes nor rejects complementary therapies. We support people being aware of choices available to them - and being able to access the information necessary to make good decisions about their healthcare. We hope that the range of articles in this edition reflects and supports our approach.

Over the last 12 months, we have published several articles on complementary therapies -

Naturally Speaking, Ses Salmond; Ed20, p24

Chinese Medicine..., Yi Sheng Chen et.al; Ed21, p28

Colloidal silver..., Stephen Barrett; Ed22, p9

Naturopathic care..., Justine Lovelock; Ed22, p29

Towards the back of each *Hep C Review* we also run a regular article on Complementary therapies.



# Interferon testing bid submitted

By Martyn Goddard

An answer is expected during 1999 on the ANCARD CTTAC (Clinical Trials & Treatments Advisory Committee) submission seeking Medicare funding of viral testing for people with hepatitis C taking interferon alpha.

The document, which draws on evidence from more than 100 published papers, was submitted to the new Medicare Services Advisory Committee. This committee examines, for efficacy and cost effectiveness, all new tests and procedures for which Medicare coverage is sought.

It is a major part of the Commonwealth government's swing towards evidence-based medicine.

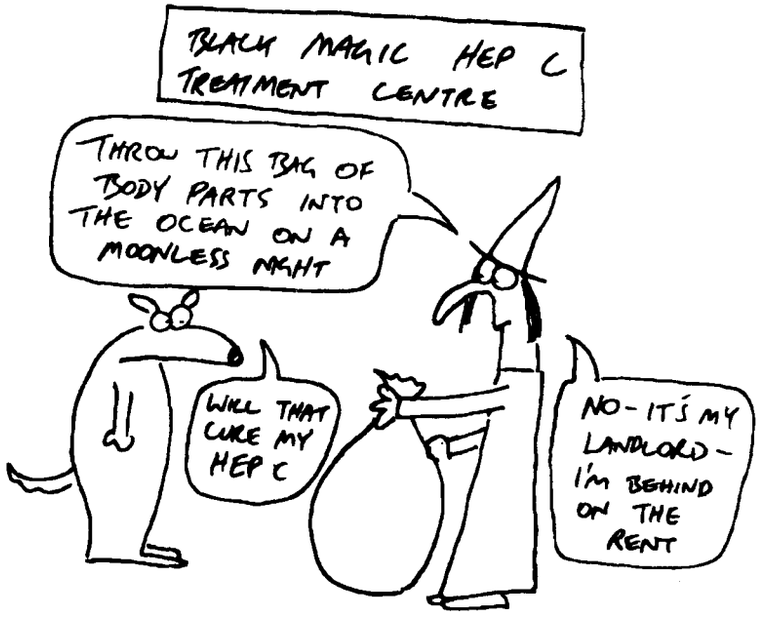
The ANCARD CTTAC submission seeks approval of a program of viral genotype, viral detection and viral load testing to predict which people with hepatitis C are likely to benefit from interferon therapy.

Currently, most do not show a sustained response [see Ed23, p16]. Used properly, the tests can tell with a high degree of accuracy who should start or continue therapy.

Supporting submissions are being made by Chiron Diagnostics and Roche Diagnostics.

An independent analysis of the technical performance of the commercial assay kits is being conducted by the National Serology Reference Laboratory.

- Taken from *CTTAC News*, Issue 7 Jan 99.



# Kennett firm on drug trials

By Madeline Coorey

Jeff Kennett has extended Victoria's controversial heroin substitute trial after renewing his opposition to zero tolerance policing.

The Premier announced yesterday that Melbourne's Turning Point Alcohol and Drug Centre, now trialling four alternatives to methadone, will receive an additional $30 million in funding.

About 1500 Victorians are testing alternatives to methadone, such as Naltrexone and morphine, as part of a three-year program run by the centre.

The new funds will keep the centre operating until at least June 2000 and, according to Mr Kennett, will address "critical gaps" in the service system.

The money will provide residential and home-based withdrawal services, accommodation for women and children with alcohol and drug problems, as well as juvenile justice initiatives and further prevention and community activities.

Mr Kennett expressed support for the Government's harm-minimisation strategy and warned against returning to the situation where drugs were treated as a criminal issue rather than as a health concern.

"I think we've got to be very aware and therefore never allow ourselves to become complacent and never allow the course that we are pursuing at the moment to be sidetracked by some who may want to introduce a new system, which will return us to the way that we dealt with the drug challenge in days past," he said. "And that is to take what they may see to be a much tougher approach, which actually cracks down and turns the drug issue to one of a total criminal act rather than, for those who are users, very much a health problem."

The harm minimisation strategy was generally understood and accepted by the community, he said. "From my Government's perspective, we have to understand that unfortunately some young people are going to experiment with drugs," he said.

"Once we accept that reality, we must also accept the need for new solutions and, of course, new initiatives."

Mr Kennett said he would support a heroin trial, such as was proposed for the ACT, if it were conducted nationally.

"I am not opposed to it but I don't want, nor do I think it's right, that any one city or State should be trialling it on its own," he said.

"I think that brings about some undesirable side-effects."

The director of Melbourne University's Health Service, Margaret Beullen, said more money was still needed for drug counselling because of the difficulties many young addicts faced in breaking their dependency.

Dr Beullen said she knew of a 17-year-old girl who had stayed off heroin for 10 days but was then told it would be three months before she could get into a residential rehabilitation centre.

- Taken with thanks from the *Weekend Australian,* 21 Nov 1998.

# How bleeding safe is war?

By Bernard Lane - High Court correspondent

In a case important for anti-discrimination law, the High Court will ask itself whether it is a soldier's job to bleed safely.

The court agreed yesterday to hear an appeal by an HIV-positive soldier, known as X, who was discharged from the Army because he would, if injured, pose a risk of infection to his comrades.

But this discrimination against X was allowable because being able to bleed safely was an inherent part of a soldier's job, the full Federal Court held.

Under federal law, an employer may discriminate if an employee's disability prevents him or her meeting the "inherent requirements" of the job.

But Walter Sofronoff QC told the High Court there was no suggestion his client could not do a soldier's job - training, running, shooting, even going into combat.

His inability to bleed safely if injured could not be an inherent part of that job, Mr Sofronoff said.

But Tom Howe, counsel for the Federal Government, said the inherent requirement test would depend on the job and, for soldiers, even peace-time training posed a risk of injury, sometimes in nonsterile field conditions.

Justice Michael Kirby suggested HIV-AIDS would be an issue for some time and the health risk posed by an infected soldier would be remote.

It is understood there are other discrimination complaints pending before the Human Rights and Equal Opportunity Commission that would be affected by X's case.

- Taken with thanks from the *Weekend Australian,* 21/11/98. (Also see Ed 22, p31)

# Anti-cirrhosis gene may lead to benefit

Scientists reversed cirrhosis in rats by injecting them with a human gene, raising hope for a new treatment for people.

The gene made the rats produce high quantities of a protein that promotes liver cell regeneration while at the same time, reducing level of cell damage.

The treatment is based on a protein called hepatocyte growth factor, or HGF. The researchers created cirrhosis in rats by injecting them with a drug. Once serious cirrhosis was established, they injected some of the rats weekly with the gene for HGF.

These rats then started producing hepatocyte growth factor - with all surviving while all untreated rats died.

The work, carried out by Dr Jiro Fujimoto of the Hyogo College of Medicine, Nishinomiya, Japan, is reported in the February issue of the journal Nature Medicine.

Trials on humans have not taken place and there is no guarantee the treatment would work in people.

- Taken from the international email list, HEPV-L.

# Up to 2,500 may have been given hepatitis C

Up to 2,500 people may have contracted hepatitis C through blood transfusions, a lawyer conducting a class action against blood banks said yesterday.

Slater and Gordon partner Mr Andrew Grech said more than 300 transfusion recipients were already seeking compensation through his firm after tests showed they had the disease.

"We don't know how many people in a similar situation are out there," he said.

"People who believe they have been infected by blood transfusions between 1985 and 1991 have a compensation right and should seek legal advice."

Mr Grech said a third of the 300 patients were from NSW, a third from Victoria and the rest from other parts of Australia.

They allegedly acquired hepatitis C through blood transfusions between 1985 and 1991, before screening procedures for the disease were implemented.

Mr Grech estimated that up to 2,500 people might have been infected throughout the country. (AAP)

- Abridged with thanks from the Sydney Morning Herald, 8/1/99. [Also see Ed 21, p8]

# Compensation case resolved out-of-court

Five individuals who claimed to have contracted HCV from blood transfusions and were having their case heard in the NSW Supreme Court, have settled their cases with the Red Cross blood bank (see Ed21, p8).

Last year Slater and Gordon took five test cases to court in NSW where patients alleged they contracted hepatitis C because of negligence by the Red Cross and five public hospitals - St Margaret's, St Vincent's, St George, Royal Prince Alfred and Maitland.

We understand that the terms of the settlement are confidential and people considering taking similar action would need to seek legal advice.

For information about your nearest Community Legal Centre, phone the NSW Hepatitis C Telephone Information & Support Service (see page 2).

# North coast herbs

Dr Tim Sladden of the North Coast Public Health Unit has confirmed that with over 120 people already enrolled, the Northern Rivers CH100 trial is proceeding well.

Northern Rivers CH100 is the second phase of the 1997 Chinese Herbal trial at John Hunter Hospital, Newcastle, and will include around 200 people randomly allocated to either taking the actual herbal formula or taking harmless, identical looking pills (placebo).

By comparing results from both groups, researchers hope to further examine usefulness of the CH100 Chinese Herbal formula and its role in dealing with hep C symptoms, and improving people's liver function and quality of life.

# US needle & syringe programs expanding

NEW YORK, Jan 05 (Reuters Health) -- Syringe programs, designed to prevent the spread of HIV among intravenous drug users, are increasing in number and scope across the United States, despite a ban on federal funding, according to researchers.

Syringe programs aim to reduce HIV infection by providing sterile syringes to intravenous drug users in exchange for used, possibly contaminated syringes.

Dr. Denise Paone and other researchers at Beth Israel Medical Center, New York, surveyed 87 syringe programs - some legal, some illegal but tolerated by local officials, and some "illegal-underground."

Twenty-nine states had at least one program in 1996, located in 71 cities, a 54% increase in the number of cities since 1994.

Eighty-four programs reported exchanging a total of 14 million syringes, an increase of 75% since 1994.

About one third of AIDS cases in the US are associated with the use of injected drugs, according to the Centers for Disease Control and Prevention. Studies show that half of new HIV cases are intravenous drug users.

Syringe programs also serve as centres for education and distribution of HIV-prevention materials, Paone and her co-authors report in the January issue of the American Journal of Public Health, a journal of the American Public Health Association.

All programs provided intravenous drug users with information about safer techniques, such as using bleach to disinfect equipment. And some of the organizations offered other health services, such as tuberculosis skin testing or treatment for sexually transmitted diseases.

But "the ability to provide large numbers of sterile syringes, as well as referrals and access to services, is clearly associated with legal status," write the researchers.

"This finding suggests that changes in syringe distribution laws ... and increased public support and funding for syringe exchange programs would have a significant positive effect on HIV risk behavior," they conclude.

- SOURCE: American Journal of Public Health 1999;89:43-46. Taken from the international email list, HEPV-L.

# Council takes on training project

A steering committee made up of healthcare industry workers, and headed by the Hepatitis C Council of NSW has taken on a brief to develop HCV healthcare worker training in NSW.

Funding is provided by NSW Health as part of the Public Health Outcomes Funding Agreements (Incentive Projects) with the Commonwealth Dept of Health & Aged Care.

Overall, the project aims to develop an integrated education and learning strategy - one that will increase coordination for information and knowledge sharing among healthcare workers. It will also involve identification of healthcare workers' roles and learning needs. Within project work, there will be an emphasis on involvement of people affected by HCV.

Initial lead-up for the project included a Council-led workshop held in 1998 and funded by the NSW Health Study Grants Program Seminar Series. The report from this workshop provides valuable insight into learning needs of healthcare workers.

# EEG tests linked to infections

More than 100 people who claim they were infected with hepatitis B at a chain of Toronto (Canada) neurology clinics are waiting for a court finding that will determine the fate of their $105 million lawsuit.

A report carried out by public health authorities blamed an infected technician and inadequate safety controls at the clinics.

Thousands of patients at the clinics had undergone EEG tests in which needle-like electrodes are placed in people's scalps.

- By Michelle Shephard, The Toronto Star. Taken from the international email list, HEPV-L.

# U.S. interferon rage bomber gets time

Taking interferon and other prescription drugs 'significantly impacted' a Colville [U.S.A.] bomb-builder involved in a daylong police standoff, a judge ruled.

But U.S. District Court Judge Fred Van Sickle also determined that the impact of the drugs on Robert Tayloe is exceeded by the danger

he presents to the community. The judge sentenced Tayloe to serve 41 months in prison on a firearms charge after Federal Defender Judy Clarke asked that he be released from jail immediately and placed on probation.

The 47-year-old former welder was prescribed interferon alpha-2b in September 1997 after he was diagnosed with hepatitis C, an illness that affects the liver. He also was given prescriptions for the anti-depressant Prozac and the anti-psychotic drugs Haldol and lithium.

"Truly, this is a case where this man wouldn't be before the court if it wasn't for the very dangerous drugs he was on," Clarke argued.

Van Sickle reduced the sentencing range after ruling that the drugs significantly reduced Tayloe's mental capacities.

"The use of interferon along with the other drugs had a significant impact on the mental state of the defendant," the judge said.

Some of the fully activated pipe bombs found in Tayloe's home in Colville were attached to propane tanks. His neighborhood was evacuated during the siege. The standoff began when Tayloe and his wife had a disagreement and she called police, who set up roadblocks after shots were fired in their direction. No one was injured and Tayloe ultimately surrendered.

The federal defender presented testimony from a psychiatrist, a neuro-psychologist and a psycho-pharmacologist - all of whom said the prescription drugs triggered Tayloe's bomb-building paranoia.

"These drugs left him alone inside a twitching and anxious body," Clarke told the court, quoting Dr. Ron Siegel of Los Angeles.

- By Bill Morlin - The Spokesman-Review January 12, 1999. Taken from the international email list, HEPV-L.

# Study rules out HCV pregnancy complications

A substantial proportion of pregnant women with hepatitis C have HCV detectable in their blood even when they are asymptomatic, according to a report from Italy.

As reported in the British Journal of Obstetrics and Gynecology (1996; 103: 325-329), Dr A Floreani and colleagues study involved 1,700 consecutive women attending an obstetrics department for high-risk pregnancies at the University of Padova, Italy.

The study found that the women with hepatitis C do not have any increased risk of obstetric complications during pregnancy and birth.

They also found that pregnancy did not appear to induce any deterioration of liver illness or disease.

- Abridged from an article from Hepatitis Weekly, June 1996. Taken from the international email list, HEPV-L.

# US prison authorities made big bucks from bad blood

A multi-million dollar lawsuit has been launched against two companies and the U.S. federal government over the shipment to Canada of contaminated plasma from U.S. prisons.

The class-action lawsuit will involve about 200 people with hemophilia infused with the prison plasma in the early 1980s who later developed hepatitis C.

They allege the companies that distributed the plasma - believed to be infected with HIV and hepatitis C - were negligent and federal regulators were also at fault.

By early 1983, U.S. companies that fractionate blood products had stopped buying prison plasma - at the request of the U.S. Food and Drug Administration - because it was widely understood that, since many inmates practised unsafe gay sex or injecting drug use, their blood posed a high risk of carrying HIV. But this didn't stop prison blood centres from selling their products to foreign companies.

The two companies involved in the law suit had won contracts to provide healthcare services to prisoners. In the process, they were also permitted to collect prisoners' blood and sell it elsewhere. The prisoners were paid $7 a unit. Each unit of plasma was sold for about $50, and half of that was handed over to the Arkansas Department of Corrections. With hundreds of prisoners donating every week, it became a profitable enterprise.

- By Mark Kennedy, The Ottawa Citizen. Taken from the international email list, HEPV-L.

  *[Australian blood supplies are recruited from the general public - and since 1990, have been screened to cull out HCV and other infectious diseases. - Ed]*

# A deep connection with you

I have been hep C positive for almost 5 years that I know of. I love reading all the *Hep C Reviews*. I've found out so much.

In 1991 very early in March I received 5 units of blood from 5 different people when I was taken to the John Hunter Hospital suffering an acute ulcer bleed.

The blood transfusion saved my life but may have also given me hep C and hep B as many doctors have told me. However I did have ear piercing several years ago so I can't be absolutely definite.

I am a mother to three wonderful daughters. Two years ago I was diagnosed with metastic cancer in my cervical nodes and a primary tumor was found deep within my tonsil some time later (I had not smoked for 7 years).

I've had three operations and 7 weeks of radio therapy. My radiotherapist at the Mater is very good. They cannot say I am cured of the cancer for 5 years.

Exactly one year ago, I began the interferon trial which I have just completed, and for 4 months I've also been taking CH100, which I find helps.

This year I completed 5 years of TAFE and I was able to cope with both the illnesses though with great stress, fatigue and pain. My dream is to teach natural resource management theory and bush regeneration.

Looking back, I doubt I would put myself through it again. However my attitude is positive in the extreme and I regularly follow several alternative therapies including massage, reiki and naturopathy. Also, I exercise regularly, especially doing lots of swimming.

I saw a nutritionist in Sydney who also gave me a personal vitamin regime and diet guidelines. It would appear that I've responded to treating my body well - which includes no alcohol ever.

Recently there has been sadness in my life. My dearest little sister also was a blood recipient at Newcastle Hospital (in 1989) and had hep C as well as ulcerative colitis.

She was very depressed through constant pain and she took her own life 5 months ago at age 36.

She was a qualified veterinary nurse and a lover of the environment and Greenpeace.

We mourn her deeply and are greatly affected. Her liver condition was active and deteriorating at the time. May she now rest in peace with no pain.

I have been trying to heal myself through poetry as has one of my other sisters and I'd like to share this with anyone who wishes.

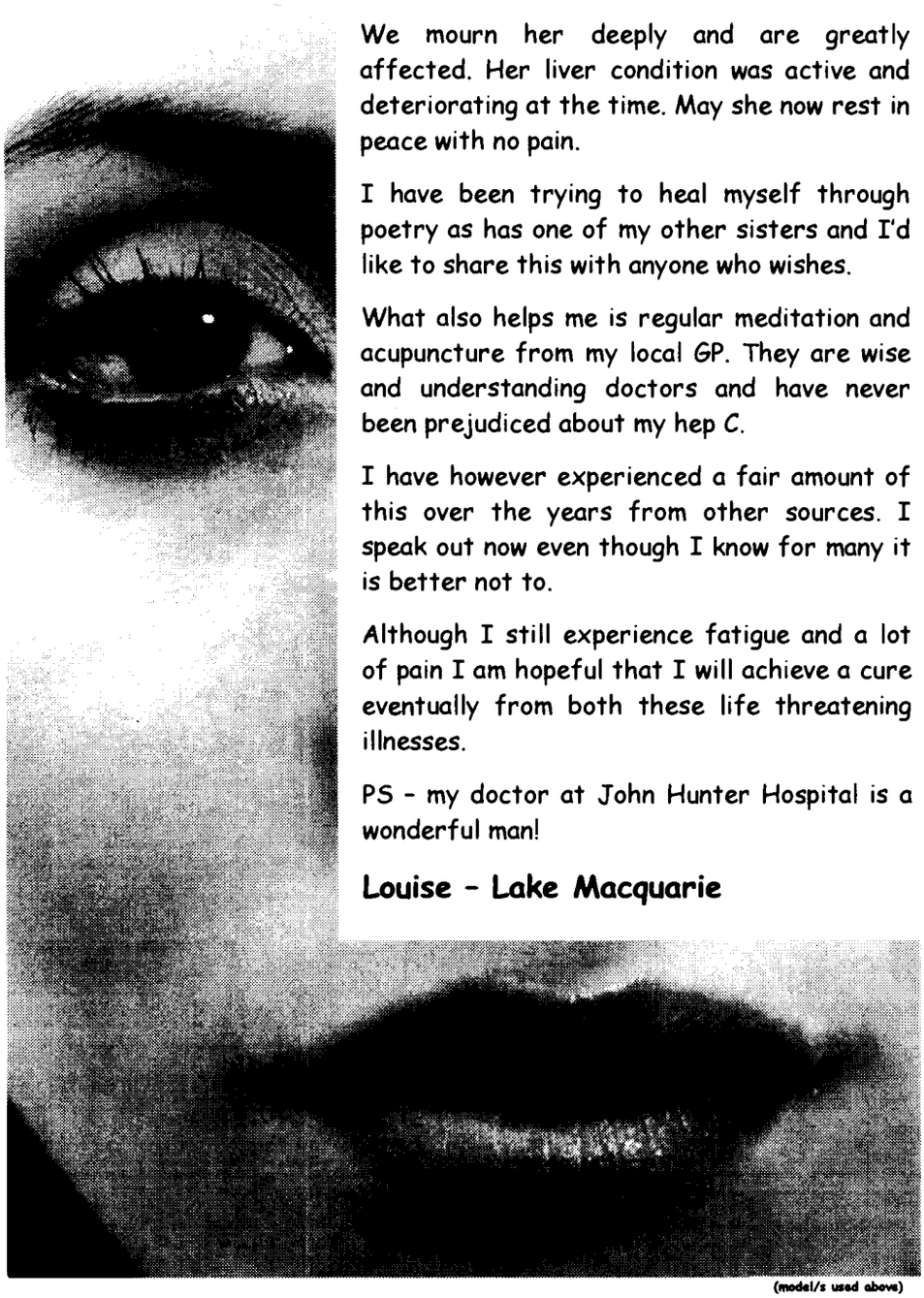
What also helps me is regular meditation and acupuncture from my local GP. They are wise and understanding doctors and have never been prejudiced about my hep C.

I have however experienced a fair amount of this over the years from other sources. I speak out now even though I know for many it is better not to.

Although I still experience fatigue and a lot of pain I am hopeful that I will achieve a cure eventually from both these life threatening illnesses.

PS - my doctor at John Hunter Hospital is a wonderful man!

**Louise - Lake Macquarie**



(model/s used above)

# The risks of untested and unregulated remedies

An editorial from the *New England Journal of Medicine* (USA).

*This article relates to the situation in the United States and the information about herbs and remedies may not necessarily relate to our situation here in Australia.* PE-SPES *for example, is not able to be prescribed as a therapeutic product here in Australia.*

What is there about alternative medicine that sets it apart from ordinary medicine? The term refers to a remarkably heterogeneous group of theories and practices - as disparate as homoeopathy, therapeutic touch, imagery, and herbal medicine. What unites them?

Eisenberg et al. defined alternative medicine - now often called complementary medicine - as "medical interventions not taught widely at U. S. medical schools or generally available at U.S. hospitals.

That is not a very satisfactory definition, especially since many alternative remedies have recently found their way into the medical mainstream. Medical schools teach alternative medicine, hospitals and [private health insurance companies] offer it, and laws in some states require [such companies] to cover it. It also constitutes a huge and rapidly growing industry, in which major pharmaceutical companies are now participating.

What most sets alternative medicine apart, in our view, is that it has not been scientifically tested and its advocates largely deny the need for such testing. By testing, we mean the marshalling of rigorous evidence of safety and efficacy, as required by the [U.S.] Food and Drug Administration (FDA) for the approval of drugs and by the best peer-reviewed medical journals for the publication of research reports.

Of course, many treatments used in conventional medicine have not been rigorously tested, either, but the scientific community generally acknowledges that this is a failing that needs to be remedied. Many advocates of alternative medicine, in contrast, believe the scientific method is simply not applicable to their remedies. They rely instead on anecdotes and theories.

In 1992, [the U.S.] Congress established within the National Institutes of Health an office of Alternative Medicine to evaluate alternative remedies. So far, the results have been disappointing.

For example, of the 30 research grants the office awarded in 1993, 28 have resulted in "final reports" (abstracts) that are listed in the office's public on-line data base. But a Medline search almost six years after the grants were awarded revealed that only 9 of the 28 resulted in published papers. Five were in 2 journals not included among the 3500 journal titles in the Countway Library of Medicine's collection. Of the other four studies, none was a controlled clinical trial that would allow any conclusions to be drawn about the efficacy of an alternative treatment.

It might be argued that conventional medicine relies on anecdotes, too, some of which are published as case reports in peer-reviewed journals. But these case reports differ from the anecdotes of alternative medicine. They describe a well-documented new finding in a defined setting.

***"the randomized, controlled clinical trial enabled researchers to study with precision the safety, efficacy, and dose effects of proposed treatments"***

If, for example, the Journal were to receive a paper describing a patient's recovery from cancer of the pancreas after he had ingested a rhubarb diet, we would require documentation of the disease and its extent, we would ask about other, similar patients who did not recover after eating rhubarb, and we might suggest trying the diet on other patients. If the answers to these and other questions were satisfactory, we might publish a case report - not to announce a remedy, but only to suggest a hypothesis that should be tested in a proper clinical trial.

In contrast, anecdotes about alternative remedies (usually published in books and magazines for the public) have no such documentation and are considered sufficient in themselves as support for therapeutic claims.

Alternative medicine also distinguishes itself by an ideology that largely ignores biologic mechanisms, often disparages modern science, and relies on what are purported to be ancient practices and natural remedies (which are seen as somehow being simultaneously more potent and less toxic than conventional medicine).

Accordingly, herbs or mixtures of herbs are considered superior to the active compounds isolated in the laboratory. And healing methods

such as homoeopathy and therapeutic touch are fervently promoted despite not only the lack of good clinical evidence of effectiveness, but the presence of a rationale that violates fundamental scientific laws - surely a circumstance that requires more, rather than less, evidence.

Of all forms of alternative treatment, the most common is herbal medicine. Until the 20th century, most remedies were botanicals, a few of which were found through trial and error to be helpful. For example, purple foxglove was found to be helpful for dropsy, the opium poppy for pain, cough, and diarrhea, and cinchona bark for fever.

But therapeutic successes with botanicals came at great human cost. The indications for using a given botanical were ill defined, dosage was arbitrary because the concentrations of the active ingredient were unknown, and all manner of contaminants were often present.

More important, many of the remedies simply did not work, and some were harmful or even deadly. The only way to separate the beneficial from the useless or hazardous was through anecdotes relayed mainly by word of mouth.

All that began to change in the 20th century as a result of rapid advances in medical science. The emergence of sophisticated chemical and pharmacological methods meant that we could identify and purify the active ingredients in botanicals and study them. Digitalis was extracted from the purple foxglove, morphine from the opium poppy, and quinine from cinchona bark.

Furthermore, once the chemistry was understood, it was possible to synthesize related molecules with more desirable properties. For example, penicillin was fortuitously discovered when penicillium mould contaminated some bacterial cultures. Isolating and characterizing it permitted the synthesis of a wide variety of related antibiotics with different spectrums of activity.

In addition, powerful epidemiological tools were developed for testing potential remedies. In particular, the evolution of the randomized, controlled clinical trial enabled researchers to study with precision the safety, efficacy, and dose effects of proposed treatments and the indications for them.

No longer do we have to rely on trial and error and anecdotes. We have learned to ask for and expect statistically reliable evidence before accepting conclusions about remedies. Without such evidence, the FDA will not permit a drug to be marketed.

The results of these advances have been spectacular. As examples, we now know that treatment with aspirin, heparin, thrombolytic agents, and beta-adrenergic blockers greatly reduces mortality from myocardial infarction; a combination of nucleoside analogues and a protease inhibitor can stave off the onset of AIDS in people with human immunodeficiency virus infection; antibiotics heal peptic ulcers; and a cocktail of cytotoxic drugs can cure most cases of childhood leukemia.

***"Once a treatment has been tested rigorously, it no longer matters whether it was considered alternative at the outset.***

***If it is found to be reasonably safe and effective, it will be accepted."***

Also in this century, we have developed and tested vaccines against a great many infectious scourges, including measles, poliomyelitis, pertussis, diphtheria, hepatitis B, some forms of meningitis, and pneumococcal pneumonia, and we have a vast arsenal of effective antibiotics for many others.

In less than a century, life expectancy in the United States has increased by three decades, in part because of better sanitation and living standards, but in large part because of advances in medicine realized through rigorous testing. Other countries lagged behind, but as scientific medicine became universal, all countries affluent enough to afford it saw the same benefits.

Now, with the increased interest in alternative medicine, we see a reversion to irrational approaches to medical practice, even while scientific medicine is making some of its most dramatic advances. Exploring the reasons for this paradox is outside the scope of this editorial, but it is probably in part a matter of disillusionment with the often hurried and impersonal care delivered by conventional physicians, as well as the harsh treatments that may be necessary for life-threatening diseases.

Fortunately, most untested herbal remedies are probably harmless. In addition, they seem to be used primarily by people who are healthy and believe the remedies will help them stay that way, or by people who have common, relatively minor problems, such as backache or fatigue. Most such people would probably seek out conventional doctors if they had indications of serious disease, such as crushing chest pain, a mass in the breast, or blood in the urine.

Still, uncertainty about whether symptoms are serious could result in a harmful delay in getting treatment that has been proved effective. And some people may embrace alternative medicine exclusively, putting themselves in great danger.

In [the *New England Journal of Medicine,* September 17, 1998 - Volume 339, Number 12] , Coppes et al. describe two such instances.

In the same edition, we see that there are risks of alternative medicine in addition to that of failing to receive effective treatment.

Slifman and her colleagues report a case of digitalis toxicity in a young woman who had ingested a contaminated herbal concoction. Ko reports finding widespread inconsistencies and adulterations in his analysis of Asian patent medicines. Lo Vecchio et al. report on a patient who suffered central nervous system depression after ingesting a substance sold in health-food stores as a growth hormone stimulator, and Beigel and colleagues describe the puzzling clinical course of a patient in whom lead poisoning developed after he took an Indian herbal remedy for his diabetes.

These are without doubt simply examples of what will be a rapidly growing problem.

What about the FDA? [U.S. Food & Drug Administration] Shouldn't it be monitoring the safety and efficacy of these remedies? Not any longer, according to the US Congress. In response to the lobbying efforts of the multibillion-dollar "dietary supplement" industry, Congress in 1994 exempted their products from FDA regulation. Homoeopathic remedies have been exempted since 1938.

Since then, these products have flooded the market, subject only to the scruples of their manufacturers. They may contain the substances listed on the label in the amounts claimed, but they need not, and there is no one to prevent their sale if they don't.

In analyses of ginseng products, for example, the amount of the active ingredient in each pill varied by as much as a factor of 10 among brands that were labelled as containing the same amount. Some brands contained none at all.

Herbal remedies may also be sold without any knowledge of their mechanism of action. In [the previoiusly mentioned edition of the *New England Journal of Medicine*], Di Paola and his colleagues report that the herbal mixture called PC-SPES (PC for prostate cancer, and spes the Latin for "hope") has substantial estrogenic activity.

Yet this substance is promoted as bolstering the immune system in patients with prostate cancer that is refractory to treatment with estrogen. Many men taking PC-SPES have thus received varying amounts of hormonal treatment without knowing it, some in addition to the estrogen treatments given to them by their conventional physicians.

***"No longer do we have to rely on trial and error and anecdotes. We have learned to ask for and expect statistically reliable evidence before accepting conclusions about remedies."***

The only legal requirement in the sale of such products is that they not be promoted as preventing or treating disease. To comply with that stipulation, their labelling has risen to an art form of doublespeak (witness the name PC-SPES). Not only are they sold under the euphemistic rubric "dietary supplements," but also the medical uses for which they are sold are merely insinuated.

Nevertheless, it is clear what is meant. Shark cartilage (priced in a local drugstore at more than $3 for a day's dose) is promoted on its label "to maintain proper bone and joint function," saw-palmetto to "promote prostate health," and horse-chestnut seed extract to "promote ... leg vein health."

Anyone can walk into a health-food store and unwittingly buy PC-SPES with unknown amounts of estrogenic activity, plantain laced with digitalis, or Indian herbs contaminated with heavy metals.

*Caveat emptor* [Latin, for buyer beware]. The FDA can intervene only after the fact, when it is shown that a product is harmful.

It is time for the scientific community to stop giving alternative medicine a free ride. There cannot be two kinds of medicine - conventional and alternative. There is only medicine that has been adequately tested and medicine that has not, medicine that works and medicine that may or may not work.

Once a treatment has been tested rigorously, it no longer matters whether it was considered alternative at the outset. If it is found to be reasonably safe and effective, it will be accepted. But assertions, speculation, and testimonials do not substitute for evidence. Alternative treatments should be subjected to scientific testing no less rigorous than that required for conventional treatments.

- By Marcia Angell, M.D. & Jerome P. Kassirer, M.D.

  For the fully referenced original, see The New England Journal of Medicine. September 17, 1998 - Volume 339, Number 12.

  You'd be able to access a copy via your nearest public or university library.

  Taken from the internet email list, HEPV-L.

# It hasn't been easy

At the age of 48 I have had hepatitis C for probably close to thirty years. This virus can hide for decades, only to pop out in the prime of a person's life. It happened to me two years ago and I have been ill ever since.

Like thousands of other baby boomers, I played with intravenous drugs in my teens and early twenties. My mother used to rail, "You're ruining your body. Someday you'll look back and realise that I know what I'm talking about!"

Yes, Mother, although you didn't live long enough to see your exhortation come true, I now bow down to your wise Crone wisdom.

Beginning in the '70s I worked in the field of drug recovery, and then I became an AIDS counsellor. Being on the front lines of HIV/AIDS work was stressful. But I gave my work my all. If I could keep one more person from acquiring the virus, comfort one more person already affected, or help one more person (mostly male) die with dignity, I felt I was being useful. I marched in parades and walkathons, spoke on television, and gave health presentations everywhere I could. Still it wasn't enough.

In 1992 I started losing friends, and they continued dying by the dozens until I eventually lost count.

In a last ditch effort to be straight, I married a man in 1989, and we later found out he was HIV positive. I also realized that I was not a bisexual; I was a lesbian. Even so I stayed with my husband, holding his hand as he died in 1993. That effectively closed one chapter of my life and opened a new one as a lesbian.

Two years later I discovered that although I had escaped HIV, I had not escaped hepatitis C. That year I got close to BJ, a wonderful, talented, amazing, butch lesbian. She also has hepatitis C, but fortunately she is not symptomatic yet. We became friends, then life partners. One month after we professed our love, I was seized with unbelievable pain, muscle spasms, drenching sweats, and paralyzing fatigue. I pushed BJ away, deciding that she shouldn't have to experience what I had gone through living with an ill person. She begged me to let her be the one to decide if she could handle my illness or not. After much soul searching, I finally opened my heart and accepted her love.

It hasn't been easy. Sometimes I have to use a cane, walker, or wheelchair. The last trip we took ended suddenly when I became ill and had to be flown back home and hospitalized. No treatments have worked.

My only real hope of survival at this late stage would be a transplant, and I'm not sure I want to go through that. I'm spiritual enough to believe in life after death - it's pain and suffering I fear. Thanks to a compassionate feminist oncologist, I'm getting medication to deal with my pain and nausea. I had three previous male doctors say virtually, "It's all in your head. Just take a tylenol or an antidepressant."

Approximately four million Americans have this illness, but due to the stigma of drug use it's basically in the closet. Doctors still choose to believe it is relatively painless illness despite the thousands of people telling them otherwise.

Sometimes I say to myself, "Where are the cans of Ensure, massages, walkathons, and support organizations mobilizing to help us?"

Here in Santa Cruz, the only support systems my sisters and I have are ones we have set up for ourselves. I want to be more politically active, but most of the time I'm too tired.

Hepatitis C is almost exclusively passed through blood. Be careful of piercing, sharing razors or toothbrushes, or other activities that involve blood exchange, including menstrual blood. If you think you may have been at risk, please get tested. Treatment is available and is most successful for people who have recently acquired the disease.

Even though hepatitis C is not passed casually, many people still fear being around us. I am lucky enough to have a wonderful lover, great friends, and a very supportive family; many lesbians have no one.

- From Bev - Santa Cruz, USA

  (Taken from the internet email membership 'list' HEPV-L)

(model/s used above)

# Caution advised on nutritional claims

Various claims are made about effectiveness of different hepatitis C treatments.

We have heard of practitioners (both medical and complementary) who claim that using their particular approach, they are able to cure hepatitis C.

Recently we noticed a printed information sheet that provides a reasonable overview of HCV but concludes with rather dubious advice about treating HCV.

Highlighting that people can prevent viruses such as hepatitis C and hepatitis B from damaging the liver, the info sheet claims that nutritional medicine can keep viruses in a "dormant or harmless state so that they do not damage liver cells".

In large bolded text it is suggested that *"To achieve this we must help the immune system ... follow the* Liver Cleansing Diet *".*

The info sheet claims that following this diet will *"repair and rejuvenate the liver".*

No one would deny that eating well will help improve a person's overall level of health and wellbeing. We are unaware, though, of any research that even attempts to show, let alone prove, whether 'nutritional medicine' has any effect on viral activity or levels of liver cell damage.

Indeed, scientists are only beginning to unravel some of HCV's secrets - how it replicates, why it causes liver cell damage, why some people are affected while others seem not to be, or whether HCV affects other parts of the body.

Being healthcare consumers, it is not always easy to 'separate the wheat from the chaff'. Asking 'experts' for proof of their claims is a good place to start.

(Also see, Helen Vidot's review of *The Liver Cleansing Diet,* page 27).



# Allan's story

After reading several of the "My Story" articles in the *Hep C Review* for a couple of editions I have decided to put pen to paper in the aim that my story might help someone who may have had similar experiences or is going through the same thing.

I contracted Hep C in September 1978 from a blood transfusion, and I did not become ill until towards the end of 1996. At the time of the transfusion I was a career soldier with the Australian Defence Force and was injured undertaking my duties.

Doctors asked if I had felt unwell at any time after this transfusion - an impossible task to think back 20 years to record how you felt and if I had been jaundiced which I may have been but being an infantry solider, I spent a large amount of time in the bush and would not have noticed and would have put any other symptoms down to working long hours and lack of sleep.

In 1996 I visited the doctor because I thought I may have had diabetes as I had the shakes if I skipped a meal. My doctor carried out a blood test which showed altered liver function levels. She felt there was a need for further investigation and referred me to a specialist. The specialist conducted more blood tests and tested for hep C which came back positive. He said that I should be tested for HIV to which I replied if I had AIDS don't you think I would be extremely sick or dead by now.

The next step was to determine the damage done to my liver and I was booked in for a liver biopsy. All the books and pamphlets I read said that this procedure at the most was mildly uncomfortable; this for me was not the case I found it highly painful. At the same time I was losing a kilogram in weight each week and because of the length of time that HCV was in my system, both myself and my wife were worried that I had cancer of the liver.

The results of the biopsy were extremely good, no cirrhosis and only mild portal damage. What a relief. I suffer from extreme lethargy and get severe pain in my liver. Both these symptoms I fought for 2 years while continuing to work. In fact my wife said that there were days when she didn't know how I got to work at all.

A couple of months ago I left work on medical retirement. I am 41 years old and since then I have felt the best in the past 2 years. I now receive the Total Permanent Incapacitated pension for Department of Veteran Affairs.

I found the information in the *Hepatitis C What you need to know* invaluable in preparing my claim and subsequent appeals as initial my claim was refused. If there is any ex-service personnel who have contracted Hep C then I would urge you to make a claim for your entitlement.

I have found that with a good diet that my liver function has improved with my ALT levels dropping from 316 to around 100.

I find it disappointing that the Commonwealth won't cover the cost of Traditional Chinese Medicine as from what I have read that the results are at least as good or if not better than that of the current medical treatments.

I was seeing a well known naturopath in our local area. My experience was that while he was treating my condition it became aggravated. He was distilling his herbs in a alcohol base and as I do not consume alcohol and have not for many years I believe that my liver reacted to the alcohol base of his formula. At the moment I am taking a Milk Thistle liver tonic in tablet form without any side affects and I am having good results.

All evidence that I have been able to obtain suggest that the herbs are as effective as the pharmacological treatments available, all though this evidence is only based on small trails. I believe that further studies backed by the government need to be under taken on herbal treatments, with the co-operation of herbal companies so that people with HCV can make a truly informed choice. It is interesting that the Northern Rivers Health Service proposes to run a six month trail of CH100 starting in January 1999.

The cost of HCV to our society in terms of health dollars is high especially with the number of new cases growing at an average of 30 a day Australia wide (*Hepatitis C The Neglected Epidemic, The Hep C Review* Dec 98). If a treatment just as effective or better than interferon can be provided at a lesser cost, then I feel that the government needs to follow it up. The growing and processing of herbs is cheaper than the manufacturing of a synthetic drug.

I think that natural and complementary medicine can work hand in hand with western medicine but there are several questions:

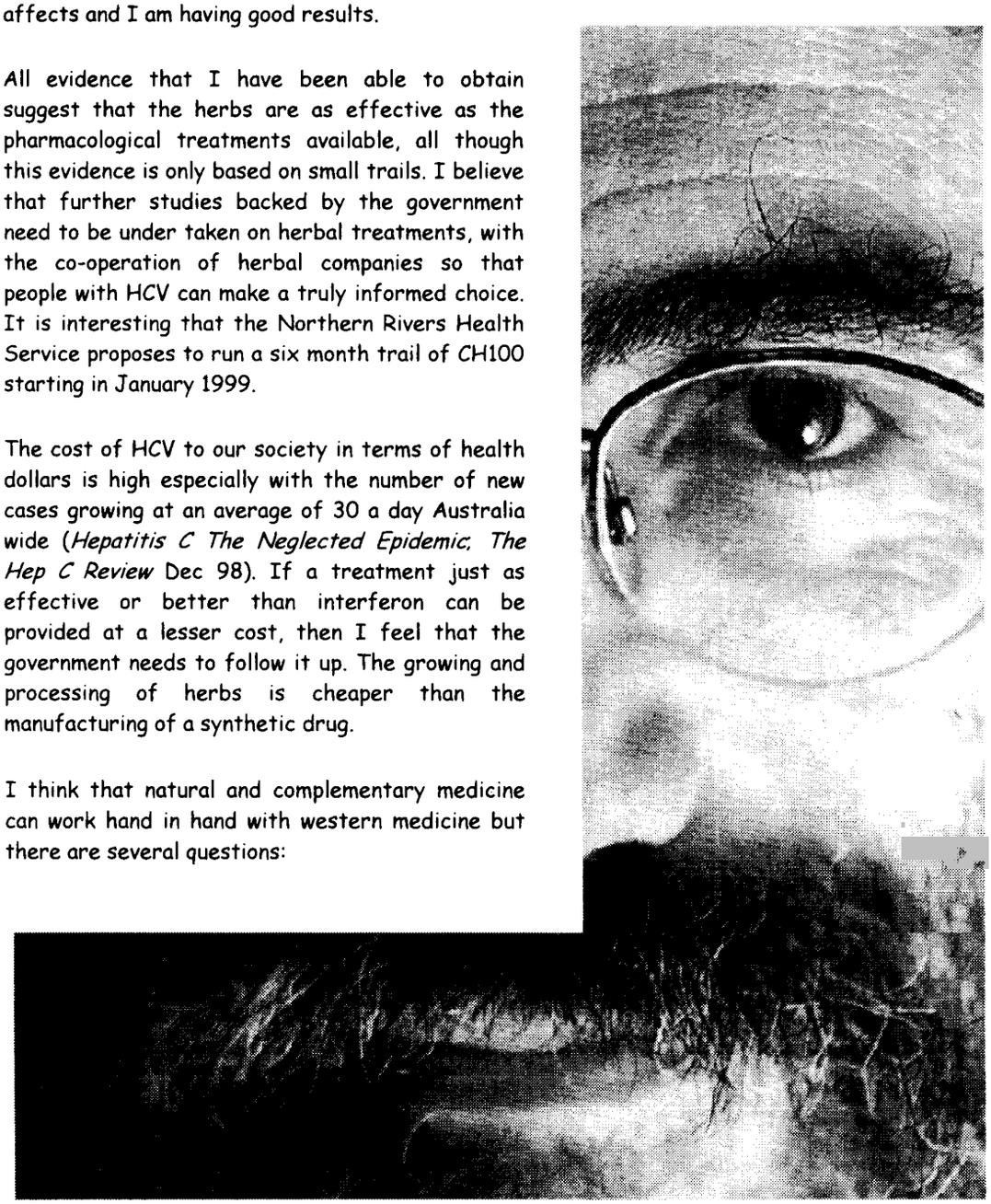
Are they over priced?

I believe that the cost is prohibitive with the average visit that I had costing between $70 and $80 with no rebate available and the fact that most people using this treatment have chronic illness and if this condition makes you unable to work or if you are in a lower income group the cost of treatment can be out of reach.

In Lismore we are fortunate that the local University as part of their naturopathy course run a clinic with low rates for people not working.

Do they require more regulation?

YES! More regulations will mean better qualified practitioners as at the moment I could read a couple of books and set up my own practice as there are no regulations.



Other questions that I would liked answered:

Why hasn't government funded research into the use of herbs?

If only 10 in 100 people with HCV go on to develop liver cancer or cirrhosis. Why the push to use interferon and interferon combination therapies?

**Alan**

*Thanks for your letter Alan. We too look forward to the results of the CH100 herbal trial.*

*Interferon and combination treatments (interferon & ribavirin) have shown limited but encouraging success. Sustained response has been shown to involve apparent HCV viral clearance from the blood. (Further research may determine whether sustained responders will experience relapse.)*

*To our knowledge, such measure of success have not been shown in any trials with complementary therapies. Ed.*

(model/s used above)

# Fatigue as a symptom of liver disease

By Mark G. Swain, MD, Assistant Professor of Medicine, Hepatologist, University of Calgary USA.

## Learning Objectives:

To understand what is currently known about fatigue in liver disease. To be familiar with the theories concerning the genesis of central fatigue.

## What is known about fatigue in liver disease?

**i) Viral Hepatitis**

Fatigue as a symptom which is commonly observed in patients seen in the clinic with chronic viral hepatitis, and fatigue can be incapacitating in some patients. However, the rigorous examination of fatigue as a symptom in viral hepatitis has only recently received scientific scrutiny.

Anecdotally, fatigue has been reported to occur in approximately 5% to 10% of patients with hepatitis C and does not appear to be associated with the severity of the associated liver disease. Recently Davis showed that patients with hepatitis C had a reduced quality of life which did not appear to improve with viral clearance after interferon treatment.

Furthermore, Foster et al. have documented, by using a validated questionnaire, that patients with hepatitis C have a significant impairment in their energy level. Interestingly, patients with chronic hepatitis B did not exhibit fatigue scores any different than control subjects.

Hepatitis C patients with a history of injecting drug use (IDU) had worse fatigue scores than hepatitis C patients with no history of IDU, but both groups had significant reductions in energy when compared with normal controls. Moreover, fatigue scores did not correlate with the severity of hepatitis as measured by hepatic histology or ALT.

**ii) Cholestatic Liver Disease**

Fatigue, lethargy and malaise commonly occur in patients with the cholestatic liver diseases, primary biliary cirrhosis (PBC) and primary sclerosing cholangitis (PSC).

Fatigue occurs in up to 86% of patients with PBC and 75% of patients with PSC and has a significant impact on their quality of life. In PBC, fatigue constitutes the worst symptom in almost 50% of patients. Moreover, fatigue scores in 25% of PBC patients are similar to those documented in patients with multiple sclerosis. Fatigue in PBC does not correlate with disease severity. Fatigue in PBC is central, not peripheral, in origin.

## Possible Mechanisms of Fatigue Genesis in Liver Disease

The specific cause(s) of central fatigue are poorly characterized; however, a number of causes of central fatigue have been suggested and investigated in patients with chronic fatigue syndrome. These theories identify sustained dysregulation of the stress response system which arise secondary to chronic physical and immune stress and which eventually lead to central changes characterized by blunting of the stress response.

This blunting of the stress response has been repeatedly implicated in the origin of fatigue in diseases characterized by chronic fatigue. These chronic stressors can be modified by psychological cofactors which modulate symptom development. These theories may be applicable to the origin of central fatigue in patients with liver disease.

Liver disease constitutes a chronic uncontrollable stress to the patient. This chronic stress can be in the form of physical, emotional and/or immune stress. Furthermore, in experimental liver disease in rats we have identified a number of abnormalities in the central systems which control the stress response. Specifically we have identified decreased hypothalamic corticotropin-releasing hormone (CRH) levels and release in rats with cholestatic liver disease and this deficit in central CRH release leads to defective CRH-mediated behaviours in these animals.

CRH is the main central activator of the stress response in rodents and humans and defective central CRH release has been implicated in the origin of fatigue in the chronic fatigue syndrome.

In addition, we have identified augmented central responsiveness of cholestatic rats to the fatigue-ameliorating effects elicited by serotonin receptor activation (specifically 5HT1A receptors). Given that serotonin activates the stress response by stimulating central CRH release, these results are consistent with enhanced sensitivity to serotonin-induced CRH release in cholestatic rats as mediating the beneficial effects of serotonin receptor activation upon

Many readers want to see more highly detailed information on hep C. The above article/s attempt to meet this need.
Although some individual research may appear to contradict current HCV beliefs, such scientific debate is of great benefit, leading to a better

fatigue in these animals. Chronic immune activation leads to hypercytokinemia in patients with chronic liver disease.

Prolonged exposure of the brain to elevated circulating cytokine levels can lead to a blunting of the stress response which has been implicated in the origin of fatigue.

We have identified elevated circulating cytokine levels in cholestatic rats and have also found a blunting of the activation of the stress response in cholestatic rats produced by acute immune activation and by exogenous cytokine administration.

These results suggest that a blunting of immune activation of the stress response in liver disease may contribute to the genesis of fatigue in patients with chronic liver disease.

## Treatment of Fatigue in the Patients with Liver Disease

i) Rule out Other Causes of Fatigue:
renal (BUN, Cr, lytes)
anemia (CBC)
electrolyte (Mg2+, Ca2+)
thyroid (TSH)

ii) Rule out Depression:
If patient is depressed consider treatment of depression and observe for improvement of fatigue

iii) Future Directions:
CRH agonists
centrally active serotonin receptor (5HT1A) agonists
anti-cytokines

- Our thanks to our Medical & Research Advisory Panel for assistance with the above abridgement.

  The fully referenced original can be found at the website address: UPDATE ON LIVER DISEASE & HEPATITIS ISSUES & CONTROVERSIES IN 1998 (http://www.hepnet.com/hepc/uldh98/swain.html).

  This research abstract was taken from the international email list, HEPV-L.

# Long term efficacy of Glycyrrhizin

By Y Arase, of the Tonanomon Hospital, Dept Gastroenterology, Tokyo Japan.

## Background:

A retrospective study was undertaken to evaluate the long term preventive effect of Stronger Neo-Minophagen C (SNMC) on HCC development. SNMC is a Japanese herbal medicine derived from licorice root that is commonly administered to patients with chronic hepatitis C to improve the serum alanine aminotransferase (ALT) level.

Of 453 patients diagnosed with chronic hepatitis C retrospectively in the study hospital between January 1979 and April 1984, 84 patients (Group A) had been treated with SNMC; SNMC was given at a dose of 100 ml daily for 8 weeks, then 2-7 times a week for 2-16 years (median, 10.1 years).

Another group of 109 patients (Group B) could not be treated with SNMC or interferon for a long period of time (median, 9.2 years) and were given other herbal medicine (such as vitamin K). The patients were retrospectively monitored, and the cumulative incidence of HCC and risk factors for HCC were examined.

## Results

The 10th-year rates of cumulative HCC incidence for Groups A and B were 7% and 12%, respectively, and the 15th-year rates were 12% and 25%. By Cox regression analysis [a particular method of scientific analysis], the relative risk of HCC incidence in patients not treated with SNMC (Group B) was 2.49 compared with that of patients treated with SNMC (Group A).

## Conclusions

In this study, long term administration of SNMC in the treatment of chronic hepatitis C was effective in helping prevent liver carcinogenesis.

- The fully referenced article can be found in *CANCER* 1997 Apr 15 ; 79(8):1494-1500

  This research abstract was taken from the international email list, HEPV-L.

understanding of HCV and its effect on people's health. To clarify any medical terminology, or for further information, please speak to your doctor or specialist, or phone the Hep C Info/Support Service : 9332 1599 (Sydney callers) or 1800 803 990 (NSW callers).

# Nothing out of the ordinary

I can safely state that my life had not been anything out of the ordinary. I was born, raised, educated and once out of high school, I began working for my father fulltime. I married my high school steady and started to raise a family. All our friends are people we've known for years and the town we live in and around is barely populated by more than 3,000 farmers and rural workers in the heartland of this country [the USA].

The only thing that happened to me out of the ordinary was on a night in June of 1977 on the main highway that led to our home. I was driving home that night after working late when I was struck head on by a drunken, out of state driver that crossed the centre line. We were both lucky to be alive and rushed to the nearest hospital some 35 miles away.

We both needed surgery and I received a blood transfusion. My broken bones healed and my head injury was nothing permanent. Life soon returned to normal and I was glad to be alive.

Besides an occasional bout of bronchitis and one time for pneumonia (I'm a smoker), I really didn't need to see our local doctor over the years. But in 1991, intestinal problems that wouldn't let up forced me to seek help.

When he asked questions about the rest of my health, I told him that I had felt a strange weariness coming on for the last year along with the stomach and bowel problems, that I lacked energy and felt like I had some flu bug at times that wouldn't go away because I felt achy all over.

I was sent home with some medicines that would take care of any parasites that might have been in the well water at home although no one else in our family, my wife and two daughters had gotten sick. I was also told to take Mylanta at times and then Donnagel for the diarrhea plus a medicine for the cramping pain. The doctor also told me to take Advil for the aches.

Nothing worked and the cramping and diarrhea forced me to stay at home for days at a time. I lost weight and it seemed to me and my wife that this wasn't a fleeting illness. There had to be something that could be done. Back to the doctor, a few different medicines and advice to change my diet and to exercise. I had no appetite and everything that I ate came out as fluid. I was too wasted at this point to exercise or work and the fluids he told me to drink all day seemed to make the situation worse.

My wife called the doctor and he wasn't very comforting when he told her that I would probably have to go to the hospital and be checked out there. He couldn't do anything more. (The local doctor who tended to us all as kids and then adults had passed away in '79 and since that time everyone had suffered through a steady stream of doctors who came and left every two to three years. This doctor was in his late forties and not happy to be in this area.)

At the hospital, I was asked about any blood work results. I hadn't had any blood drawn by the local doctor so I told them that. I was there for about four hours that day. Blood was drawn and two doctors asked me a string of questions. They thought I was dehydrated so I got some IV solution. I was told to make an appointment with one of the gastroenterologists at the hospital the next day.

That was the beginning of a long ordeal that eventually resulted in a diagnosis of hepatitis C from the blood transfusion in 1977. However, while the doctors fussed around with their blood tests and medicines and upper and lower GI tests, I got worse.

We didn't know the first thing about the blood test results and depended on the doctors to know what was going on. From that first trip to the gastroenterologist, my liver enzymes were high. They were never mentioned to us at the time. Three months later, an ultrasound test was done and we were told that I had gallbladder problems. A month later, my gallbladder was removed.

For me at least, recovery from that surgery was tough because I still didn't feel right. Besides the aches and fatigue, I had been feeling sick to my stomach, very weak and had trouble sleeping because of itching and night sweats.

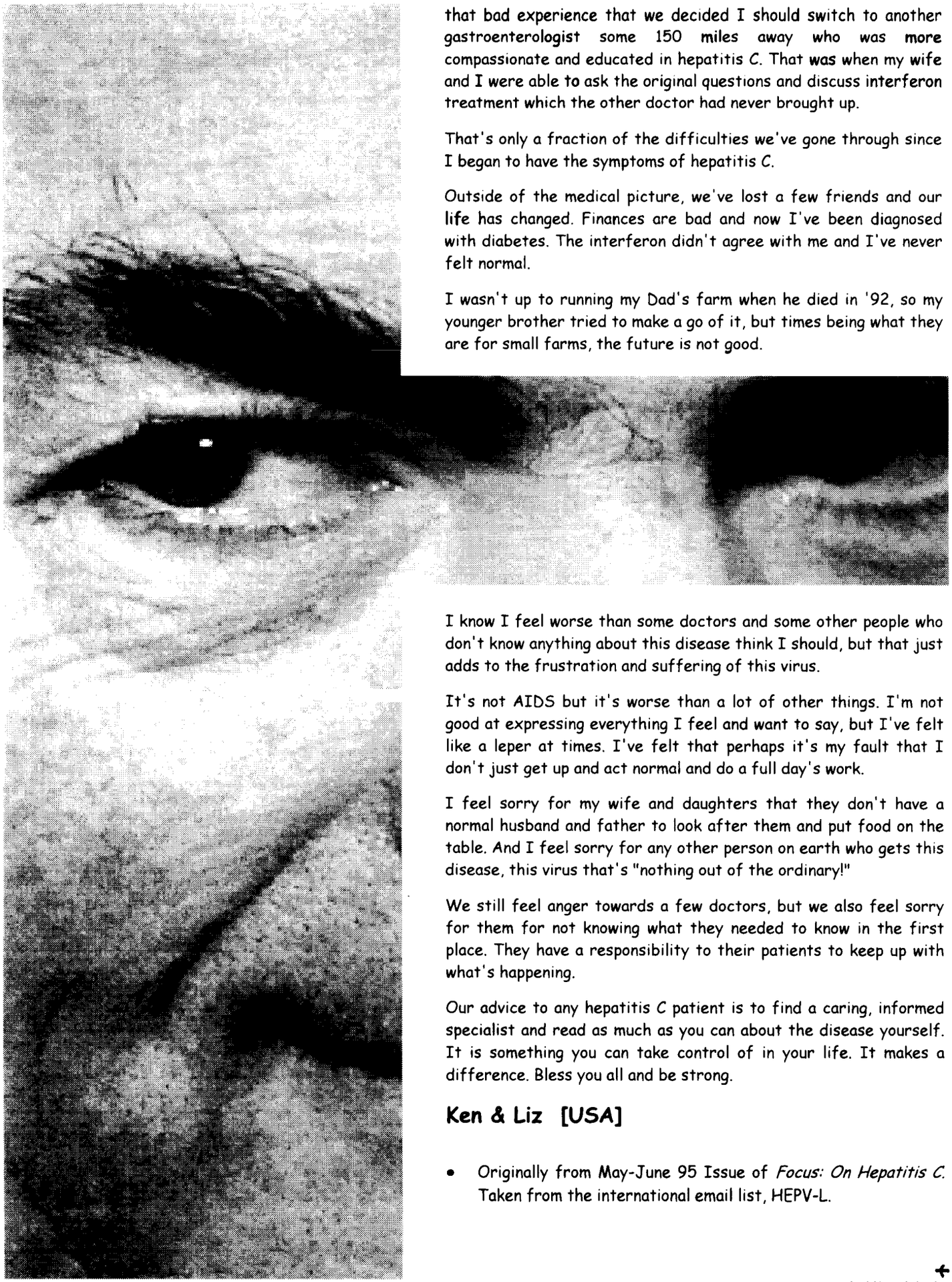
Two months later, I was tested for all the hepatitis viruses and that's when we discovered that I had hepatitis C. The gastro guy told us, "Well, you've got hepatitis C, but it's nothing out of the ordinary. It's a mild hepatitis that shouldn't bother you much over the years."

And the way he told us this sounded like what I had already gone through wasn't bad or connected to the hepatitis C. We asked him about that. He told us that it was all the gallbladder problem and not to worry because I would notice an improvement in my health shortly.

The improvement was slow to come over the weeks and then months that followed. Eight months later, I was told that a liver biopsy might be a good idea so that was done. Then we were told that I had chronic active hepatitis.

My wife did some research on hepatitis C and had a lot of questions to ask the doctor the next time we saw him. When she started to ask the questions, he waved his hand and told her, "Your husband doesn't need answers to those questions. He needs to get better on his own."

We still don't know what that meant. Then he told us that there wasn't a lot of information known about hepatitis C, but that it wasn't AIDS or nearly as bad as hepatitis B. It wasn't long after



that bad experience that we decided I should switch to another gastroenterologist some 150 miles away who was more compassionate and educated in hepatitis C. That was when my wife and I were able to ask the original questions and discuss interferon treatment which the other doctor had never brought up.

That's only a fraction of the difficulties we've gone through since I began to have the symptoms of hepatitis C.

Outside of the medical picture, we've lost a few friends and our life has changed. Finances are bad and now I've been diagnosed with diabetes. The interferon didn't agree with me and I've never felt normal.

I wasn't up to running my Dad's farm when he died in '92, so my younger brother tried to make a go of it, but times being what they are for small farms, the future is not good.

I know I feel worse than some doctors and some other people who don't know anything about this disease think I should, but that just adds to the frustration and suffering of this virus.

It's not AIDS but it's worse than a lot of other things. I'm not good at expressing everything I feel and want to say, but I've felt like a leper at times. I've felt that perhaps it's my fault that I don't just get up and act normal and do a full day's work.

I feel sorry for my wife and daughters that they don't have a normal husband and father to look after them and put food on the table. And I feel sorry for any other person on earth who gets this disease, this virus that's "nothing out of the ordinary!"

We still feel anger towards a few doctors, but we also feel sorry for them for not knowing what they needed to know in the first place. They have a responsibility to their patients to keep up with what's happening.

Our advice to any hepatitis C patient is to find a caring, informed specialist and read as much as you can about the disease yourself. It is something you can take control of in your life. It makes a difference. Bless you all and be strong.

**Ken & Liz [USA]**

- Originally from May-June 95 Issue of *Focus: On Hepatitis C.* Taken from the international email list, HEPV-L.

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(model/s used above)

# Naturopathy

Abridged & adapted from an article by Mary & Michael Morton.

## Basic principles

Naturopathy's basic principles are:

*Utilize the Healing Power of Nature*: Nature acts powerfully through the healing mechanisms of the body and mind to maintain and restore health. Naturopathic therapists work to restore and support these inherent healing systems when they have broken down, by using methods, medicines, and techniques that are in harmony with natural processes.

*First Do No Harm*: Naturopathic therapists prefer non-invasive treatments, which minimize the risks of harmful side effects. They are trained to know which patients they can treat safely, and which ones they need to refer to other health care practitioners.

*Find the Cause*: Every illness has an underlying cause, often an aspect of the lifestyle, diet, or habits of the individual. A naturopathic therapist is trained to find and remove the underlying cause of a disease.

*Treat the Whole Person*: Health or disease results from a complex interaction of physical, mental, emotional, dietary, genetic, environmental, lifestyle, and other factors. Naturopathic therapists treat the whole person, taking these factors into account.

*Preventative Medicine*: The naturopathic approach to health care can prevent minor illnesses from developing into more serious, chronic, or degenerative diseases. Patients are taught the principles with which to live a healthy life; by following these principles, they can prevent major illnesses.

Above all, naturopathic therapists respect the natural healing power present in all systems of the human body and they attempt to focus and mobilize that power in their treatment process. Therapists have found that this natural healing power, if effectively mobilized, can destroy invading organisms, cast off toxins, as well as rebuild strength and vitality.

It may surprise some people to know that some naturopathic therapists and Medical Doctors (MDs) have some areas of common ground, namely their education. MDs are schooled in basic sciences and clinical sciences to prepare them for the various illnesses and emergencies they will face during their practice. Some naturopathic therapists are also well trained in all these sciences in their education. But, unlike MDs some are also trained in a variety of traditional natural therapeutics, including botanical medicine, clinical nutrition, homoeopathy, acupuncture, traditional Chinese medicine, hydrotherapy, and naturopathic massage therapies.

Naturopathic therapists learn how to integrate this diverse knowledge by combining their conventional medical education with the goal of providing superior health care in their practices. They weave their conventional medical knowledge with the principles of naturopathic medicine and its treatments to create a natural health care program tailored for each individual patient.

## A range of treatments

In the past few years, naturopathic medicine has won the respect of federal and state government bodies, members of the conventional medical community, educators, celebrities, the media, and an ever-increasing number of Australian health care consumers. A main reason for naturopathic medicine's rise in popularity is its common-sense use of simple yet tremendously effective natural treatments. These treatments include:

### Clinical Nutrition

Clinical nutrition has been one of the main cornerstones of naturopathic medicine since its inception. Studies from around the world, in a variety of medical traditions, have validated the benefits of naturopathy's nutritional principles. A vast number of documented cases of physical problems, including heart disease and liver conditions, have been helped by nutrition, without unpleasant side effects or complications.

Naturopathic theory suggests that most illnesses are caused by digestive disturbances, which have led to a toxic environment in the body. If the body is overwhelmed by toxins it cannot eliminate, the health or strength of the body breaks down and symptoms of various illnesses surface. Nutritional changes are a main component to changing the diseased situation because today's processed foods and poor eating habits are the source of many of the body's toxins.

To treat chronic illnesses, many times nutritional changes are the first step toward healing in naturopathic medicine. For example, simple vegetable soups are often recommended because, as they are easy to digest and assimilate, they provide the body with vitamin and mineral nutrients without adding toxins to the body.

### Hydrotherapy

If nutritional therapy is the first cornerstone of naturopathic medicine, then hydrotherapy is the second. Hydrotherapy improves digestive function by bringing additional blood (and all of its healing components) to the inner organs. The most common form of hydrotherapy is called the "constitutional," where two towels dipped in

hot water, then squeezed, are placed on the front of the patient for five minutes. The hot towels are replaced with one cold towel for ten minutes. The same procedure is done on the back of the patient. During the hot portion of the hydrotherapy, the upper blood vessels are dilated while the deeper ones constrict. The cold portion of the treatment constricts the outer blood vessels but dilates the internal ones. The combination drives more blood to both the inner and outer systems, allowing the body to bring more healing nutrients to its organs and to carry away toxins.

## Homoeopathy

Homoeopathy is used by many naturopaths and is a primary treatment in their practices. Based on the "law of similars," it uses minuscule doses of naturally occurring substances to treat illness. Naturopathic therapists have found that homeopathy fits well into their philosophical principles, since it stimulates the body's own immune system without producing unpleasant side effects. It is also documented to be effective for many illnesses, including migraines, headaches, rheumatoid arthritis, acute diarrhea, flu, and allergies. The history of homoeopathy's use spans two hundred years. Many countries embrace it as a viable healing treatment, including England, whose Royal family retains the services of a homoeopath for their personal health care.

## Herbs

Herbs are used by naturopathic therapists as medicine. As such, they can be extremely powerful and beneficial when used in the right dosage and in the correct combination with other herbs. Though herbs are the main ingredient for some of the drugs used in conventional medicine, naturopathic therapists use herbs in a different manner than MDs use them. Most drugs prescribed by MDs are intended to impose an external order on the body.

For example, a medicine prescribed to lower blood pressure forces the body to lower the pressure but doesn't correct the reason why the body has increased the pressure in the first place. Therefore, many patients taking blood pressure medicine as prescribed by a conventional medical doctor must continue to take blood pressure medication for the rest of their lives. Regrettably, the patient also endures the probable side effects: impotency, sexual dysfunction, and nervousness.

In contrast, a naturopathic therapist's goal is not to impose an outside order but to correct the underlying problem. In the case of a weakened heart, a naturopathic therapist would accomplish this by using herbs that nourish and strengthen the heart, such as hawthorne berry, or herbs that disperse congestion or toxins in the body, such as dandelion root. When strengthening and detoxification occur a patient's vitality becomes stronger, the root cause of the illness is addressed, and a permanent recovery becomes possible.

## Chinese Medicine

The treatments and diagnostic techniques as well as the fundamentals of Chinese medicine are a part of all naturopathy training at the accredited medical colleges. Some naturopathic therapists do advanced training and become practitioners of Chinese medicine, using Chinese herbs, acupuncture, and acupressure in their practice. The techniques of Chinese medicine can bring impressive and surprising results to many health care challenges and is considered an exceptional treatment for acute and chronic pain.

## Counselling and Stress Management

Naturopathic therapists believe the patient's emotional and psychological makeup can greatly influence the patient's ability to heal. Therefore, they are trained in many psychological techniques, including counselling, stress management, hypnotherapy, biofeedback, and nutritional balancing.

## Ayurvedic Medicine

Ayurvedic medicine is an ancient system of holistic medicine and healing from India. Its focus is on treating the whole person with diet, nutrition, and lifestyle recommendations. One of the key components of this system of healing is an appreciation of the role that one's vital energy, called "prana," plays in the healing process. As a result, some naturopathic therapists have earned specialty degrees in Ayurvedic medicine and have incorporated it into their practices.

## Physical Medicine

Naturopathic therapists use a combination of massage therapies, which move soft tissue as well as skeletal bones. These are collectively called 'naturopathic remedial therapy' and in some ways are similar to the techniques used by osteopathic physicians, chiropractors, massage therapists, and body workers in that structure is realigned to support the innate healing process of the body.

Not all naturopathic therapists use this as a major component of their practice. However, when other treatments fail to bring the desired response, then manipulative therapies can be helpful.

Misalignment of the spinal vertebrae as well as other skeletal structures can be the cause of pain or even illness in some cases. The return of vertebrae, bones, and joints to their optimal position can eliminate pain in as little as one treatment.

# Conditions that respond well to naturopathy

Naturopathic therapies are beneficial for a wide range of physical illnesses and conditions. Naturopaths claim that their ability to determine the underlying cause of the illness and to stimulate the body's own healing ability is why their medicine can be so effective where other systems of medicine are not.

Another area where naturopathic therapies have proven to be effective is in preventative medicine and health maintenance.

Whether patients need help in health maintenance or a reversal of a devastating disease, naturopathic therapies are a viable option worthy of consideration.

# Finding a practitioner

As yet, naturopaths have not been registered as a profession by the Australian Government. However within individual Australian states, different types of practitioners may be required to belong to an accredited professional membership body in order to practise.

*[Within each edition of The Hep C Review we publish a listing of professional bodies who can provide referrals to their members in your locality.]*

An initial referral by a satisfied client - word of mouth - is an excellent way to meet a therapist. If you decide to try the skills and expertise of a naturopathic therapist, use the following questions to help you make your decision.

## Step One: get good referrals

To locate an Australian Natural Therapies Association practitioner in your local area, phone 1800 817 577.

## Step Two: screen the candidates

Once you have a few naturopathic therapists to investigate, call their offices and ask to speak to someone on the staff. Asking well-targeted questions can assist you in determining if this is a good practitioner for you. Here are a few suggestions:

- ***What was their training?***

Practitioners who are accredited members of professional membership bodies - such as ANTA - study a vast range of subjects including medical sciences, clinical diagnosis, pathology, naturopathic philosophy, iridology, nutrition, herbal medicine and homeopathy. These are just a few of the basic requirements for a 3 year Diploma / Advanced Diploma Course and a 4 year Bachelor Degree Course.

There are many subjects that are incorporated into courses offering each practitioner the opportunity to specialise and continue to advance their ongoing education in a particular area.

In order for naturopathic therapists to maintain their membership within a professional membership body they must continue to study, either by furthering their education with Bachelor Degree level courses or by attending Continuing Professional Education seminars and workshops.

- ***Do they have experience with my condition?***

Find out how many patients with your health care problem this naturopathic therapist has successfully helped. The higher the number of successes by the naturopath, the better for you.

- ***What is their specialty?***

In most cases, in naturopathy, the answer to this question will be given in the types of treatment the naturopathic therapist specializes in rather than in specific physical conditions.

- ***Do they use health care techniques not taught in his or her formal training?***

If so, what are they, what training has the naturopathic therapist had in them, and how long have they used them in practice?

Naturopathic education includes a wide variety of complementary health care therapies, but not all. Make sure your naturopathic therapist is well trained in any technique that he or she may recommend for your recovery. Check for credit hours, professional body accreditation, and certificates of completion.

Generally speaking, there are four types of practitioners who call themselves "naturopaths" that you will find:

The first type of practitioner:

- Has graduated from an accredited naturopathic school
- Is a recognized member of an accredited professional membership organisation - eg. Australian Natural Therapists Association.

  *This practitioner is qualified to see you for almost any health condition.*

The second type of practitioner:

- Has not graduated from one of the accredited naturopathic schools
- May have received a degree or certification from a correspondence school
- Has at least seven years of clinical experience through apprenticeship with a qualified naturopath coupled with full-time personal practice

*This practitioner may be qualified enough to help you. However, it is essential that you investigate their exact education and training to make sure they are competent for your needs.*

*Finding a naturopathic practitioner who is not a member of an accredited professional membership organisation and yet is also well trained and experienced is unusual, but not impossible.*

The third type of practitioner:

- Has not graduated from one of the accredited naturopathic schools
- Received his or her degree from a correspondence school
- Has not gained enough training and experience to competently treat you in naturopathy

*We do not recommend that you work with practitioners in this category.*

The fourth type of practitioner:

- Has no formal educational training
- Has voluntarily designated him - or herself - a "Naturopath"
- Has little or no training to competently treat you

*Working with someone in this category can be dangerous. We do not recommend practitioners in this category.*

Step Three: interview the candidate

During an interview with a naturopathic therapist, find out the personal philosophy of the naturopath. Talk to them about what their ideas are about the nature of disease, the nature of your problem, and what approach they would take to improve it. Ask how long they could expect improvement to take and what kinds of costs are involved. The most important thing is to get a sense of who this person is, what they have to offer, as well as their credentials. You are an individual. So choose someone who fits with you.

If you're looking for a naturopathic therapist who is caring and capable, you may find your search fairly easy since naturopathic therapists value the healing power that can happen in the relationship between therapist and patient. Most take the time and effort to develop a good rapport with their patients.

# What to expect during a naturopathic appointment

As mentioned earlier in this article, naturopathic therapists use specific treatments that can include homeopathy, Ayurveda, and Traditional Chinese Medicine, or the traditional naturopathic approach of nutrition, herbal medicine and remedial therapy in their practices. Although there are standard procedures that all naturopathic therapists use, these "specialties," in addition to the specific health condition of the patient, make a session with each naturopath a unique experience.

## The office visit

Many naturopathic therapists send questionnaires to new patients that ask many personal health history questions. During a first visit, which usually lasts about an hour and a half, these questionnaires are reviewed.

In addition, the practitioner will ask many lifestyle questions regarding diet, vitamin and mineral supplements taken, sleep patterns, work conditions, smoking habits, and sugar and coffee intake. In addition, some standard medical diagnostic tests are administered, such as a physical exam, iridology, and blood and urine tests.

Once an naturopathic therapist has made a diagnosis, the treatments prescribed will be based on the therapists adherence to the fundamental principles of naturopathy and to their specialty. Sometimes therapists will give their patients a choice of treatments if they have a preference.

Generally, follow-up visits with an naturopathic therapist last between thirty and forty-five minutes and involve a continuation of the treatment plan as well as an evaluation of progress.

# Closing thoughts

Naturopathic therapists are filling an important need as primary health care providers who are experts in nontoxic, noninvasive treatments. Highly skilled and well educated about the human body, they bring the best of ancient natural treatments and scientific research to their medicine.

- Abridged from an original article taken from the website: http://www.healthy.net/library/articles/morton/naturo.htm
  The original article was excerpted from *Five Steps to Selecting the Best Alternative Medicine* , New World Library.
  Assistance with abridgement was provided by the Australian Natural Therapists Association (07 5492 8206).

NB: The Council does not confirm that all information within this article is based on fact. The Council neither promotes nor rejects complementary therapies. We support people being aware of choices available to them - and being able to access the information necessary to make good decisions about their healthcare.

# Regulate to succeed

Regulation raises a whole host of issues ranging from what are natural therapies, to what is a qualified practitioner and what products and treatments can be prescribed.

For herbalist David McLeod, some form of regulation is inevitable. As president of the National Herbalists Association of Australia, he sees the need to ensure regulation is practical and allows natural health practices to grow in line with community demand.

While some practitioners opposed any regulation, McLeod believes natural health has become too big for government and the 'traditional' health industry to ignore.

"We've had to withstand lots of campaigns - front on and underhand - to bury natural treatments, but the public has voted with their feet," he said from his practice, in rooms between two specialists in Brisbane's prime medico strip, Wickham Terrace.

"We're fighting what seems to be an AMA strategy to have doctors help patients fill in their 'Adverse Reaction' reports emphasising any natural products.

"The recent scare campaign on echinacea was based on a couple of doctor Adverse Reaction reports.

"That seems to stir up concerns in the public about natural products.

"It's funny how they seem to rush to the TV shows when echinacea has one adverse report, but remain silent when drugs are reported with adverse reactions.

"I've never had an adverse reaction to echinacea. In Germany it is prescribed by doctors and often by injection, by-passing the stomach's immune system. Yet very few adverse reactions are seen.

"We've tried - and sometimes succeeded - in getting onto the media to put forward the facts about natural health treatments and products.

"It's important not to be trampled on by those who don't want us to be around upsetting the traditional, institutionalised Australian medical system."

## Political promises

The fact that all political parties promise better access for natural therapies indicates that politicians have got the clear message from the community.

"None of the political parties are now anti-natural therapies - which has been a major advance in the last few years.

"They just don't know what to do about us - and are especially worried about the cost implications. They see that if natural medicine was on Medicare, the health bill would blow out even more than it has already.

"There's an issue that health is increasingly seen as a money item, not a well-being one.

"The Democrats suggest the Medicare levy could be increased to three percent, and natural health as well as a number of other treatments, such as dentistry, could be covered.

"I think we can leave that well down the track because it would raise the type of regulation we don't want.

***"The dilemma - this industry has a mix of well trained professionals and those who've done a weekend course."***

"Doctors who practise natural medicine say Medicare is very restricting - there's a lot of restrictions on tests and time.

"A natural health practitioner will want to spend time with a person and perhaps do lots of tests before finding what's really wrong - and that's not how Medicare, working to a very tight budget, works."

An important message that must be pushed is that natural health is positive health care.

"We're concerned about improving health, not treating a disease, so we're more likely to keep people out of hospitals and off expensive prescriptions.

The National Herbalists Association of Australia, founded in 1920 and with 1700 members, claims to be the biggest natural health association of herbalists.

A critical issue is to keep some control of regulation with the natural health sector, so they would prefer to see co-regulation or registration, rather than government just impose regulations.

But co-regulation or registration requires the Association to accept some form of regulation, some form of independent Complaints Tribunal and standards of practitioners which win public confidence.

Because of the broad spread of natural and alternative practices and therapies, this will eventually mean regulation by modality.

The first step is registration of practitioners in modalities which are well accepted in other countries. This would be following the path of the chiropractors who set standards and introduced them over a number of years so that now all chiropractors are registered.

With Victoria proposing that Traditional Chinese Medicine practitioners be registered, this could start the ball rolling.

- Abridgement of an article from *Natural Health Review.* Vol 1, No 1 July/Sept 1998. (Above boxed quote appeared in the original article).

# The Liver Cleansing Diet

## - a review by Helen Vidot.

The Liver Cleansing Diet, by Dr Sandra Cabot, is an easy to read book that contains some very good medical and dietary information.

Unfortunately, it also contains misleading and incorrect medical and dietary information that has little biological or clinical basis, including:

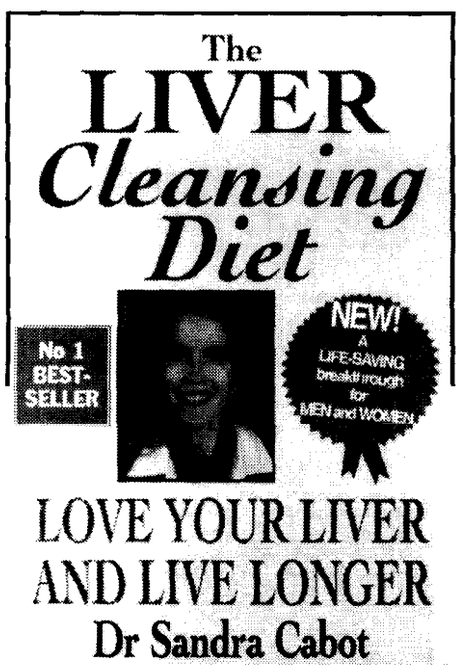
"Those who test positive for hepatitis B and/or hepatitis C and are chronic carriers of these viruses will have less chance of developing chronic liver disease if they follow the diet.

"The liver definitely needs more help after the age of 55, *as liver weight and volume decreases with age.*

"Poor liver function can manifest as high blood pressure.

"Artificial sweeteners ... cause hypoglycaemia and fatigue.

"Refined sugar and flour cause the liver to work much harder."




The Liver Cleansing Diet (LCD) subscribes to a certain philosophy of life that requires a blind faith to follow the regime described by the author.

The claim that the LCD may prevent progression of liver disease with hepatitis B or C is of concern to all who work with liver disease. Dietary change has not been shown to reduce the chance of developing chronic liver disease.

Over one third of the book is devoted to recipes. These are an interesting collection and may be useful to healthy individuals looking for something different.

But there are some major nutritional deficiencies in the LCD. If this diet is balanced, one wonders why it is necessary to take massive doses of dietary supplements.

The major nutrients concerned include iron, calcium and riboflavin. It is suggested that followers of the LCD avoid red meats and chicken for a period of four weeks. Red meat is the best source of available dietary iron as it is more difficult to absorb from other sources. Iron deficiency can be a major problem for people with chronic liver disease.

It is unclear on reading the book why dairy products should be avoided. If the aim of the diet plan is to reduce dietary fat intake, there is a wide range of low-fat or reduced-fat dairy products that could be used. Although avoidance of dairy fat often seems to be part of alternative nutritional advice, it is not usually warranted.

The LCD is a low fat diet with an overall emphasis on weight loss. There is no doubt that the LCD will help to control body weight and may lower cholesterol levels.

But weight loss in those who have liver disease is not generally recommended. As the condition progresses, the body's energy requirements are greatly increased. Fat deposits which are the body's energy stores are rapidly used up. A 10 kilogram weight loss over eight weeks is potentially harmful for those with liver disease.

The LCD also demands a high fluid intake. This is frequently unhelpful with people who have liver disease because of fluid retention often associated with liver disease.

Much of the diet is based on the assumption that the liver is dirty and needs cleansing and that we all need to rejuvenate our liver in order to relieve a variety of disorders frequently unrelated to liver disease.

But one of the many roles of the liver is to remove the waste products of metabolism and toxins from our body. It is not necessary to cleanse the liver as the liver does this itself.

Unlike many of the other organs in the body, the liver does not age. Its size and function is unaffected by the ageing process. The size of the liver is related to body weight and it does not shrink with age as the author states.

In summary, the LCD has an interesting collection of recipes that readers may wish to explore. But the diet plan is not recommended, and may in fact be harmful for those people who already have liver disease.

The Liver Cleansing Diet will not provide a cure for liver disease and may result in compromising the nutritional status of those with liver disease. It may be of some use for healthy individuals who have no pre-existing illness.

- Helen Vidot is a dietitian at the Australian National Liver Transplant Unit, Royal Prince Alfred Hospital, Sydney.

# Promoting evidence based alternative medicine

By Michael Hensley and Peter Gibson

Alternative medicine is an integral part of the healthcare of many Australians. Approximately half of our population use at least one non-medically prescribed alternative medicine each year, and about 20% of Australians visit an alternative medicine practitioner. The estimated annual expenditure is over $900 million. There are probably many reasons for this widespread use of alternative medicine; one that has been suggested is a growing dissatisfaction with orthodox medicine. That alternative medicine is of increasing relevance to orthodox medicine is illustrated by the finding that almost two-thirds of United States medical schools have courses on alternative or complementary medicine.

Despite the demand for alternative medicine, there is a lack of rigorous evidence about its effectiveness; there are few studies, and those that exist are often inconclusive. For instance, a review of existing research reports of placebo-controlled trials of homoeopathy found "insufficient evidence that homoeopathy is clearly efficacious for any single condition", but interestingly, that homeopathy may be better than placebo for seasonal allergies and postoperative ileus [non-functioning gut following surgery]. On balance, it must also be acknowledged that there are many gaps in the evidence about the effectiveness of orthodox medicine; however, orthodox medical practitioners are increasingly committed to evidence-based practice.

***"studies reinforce the need to improve the quality and quantity of evidence that is used to guide healthcare practice. This applies equally to both alternative and orthodox therapies."***

A major challenge for evidence-based orthodox medicine is the availability of high quality clinical studies to form its evidence. For alternative medicine, there is a similar, if not greater, challenge that is demonstrated in [the Medical Journal of Australia, 7/21 Dec 1998].

Liu and Douglas (page 579) reviewed published reports (in English and Chinese) on the use of Chinese herbal medicines for acute respiratory infections (ARI); Bowler et al (page 575) studied the efficacy of Buteyko breathing techniques (BBT) in the management of asthma. Both articles highlight the difficulties in designing and implementing clinical research for interventions outside of the double-blind randomised controlled trial (RCT) of conventional drug therapy.

In the systematic review of Chinese herbal medicines for ARI by Liu and Douglas, we learn of 27 studies that evaluated these products using RCT or controlled clinical trial methods. Although it is clear that scientists are trying to establish the efficacy of alternative therapies using widely accepted methods, the quality of the studies was insufficiently rigorous to allow conclusions to be drawn about the efficacy of herbal medicines. Specific problems with the reports included inadequate information about randomisation, and doubts about the quality of outcome data and statistical analysis. Liu and Douglas did identify one preparation, Shuang Huang Lian, as a promising remedy [for acute respiratory infections] worthy of further study. The reviewers identify approaches that may lead to more rigorous evaluation of this form of alternative medicine.

The evaluation of BBT by Bowler et al was designed to overcome many of the limitations in clinical methodology that occurred in the trials of Chinese herbal medicines. Buteyko breathing techniques are based on the premise that the pathophysiology in asthma is due to hypocapnia [low carbon dioxide levels in the blood] as a result of hypoventilation [over-breathing]. Participants are taught a series of exercises that purport to correct hyperventilation and hypocapnia. As well as comparing BBT with placebo breathing and relaxation exercises for managing asthma, Bowler et al addressed the question of mechanism of action by testing directly whether BBT corrected hyperventilation and hypocapnia.

They found no benefit of BBT compared with placebo breathing and relaxation techniques on objective measures of asthma, such as forced expiratory volume in one second, peak expiratory flow, and

exacerbation, despite the study having adequate power to detect an important difference. However, there were important changes in other outcomes, including a significant reduction in the self-reported use of short-acting bronchodilators and trends for reduction in the self-reported use of inhaled steroids and for improved quality of life.

An additional observation of the study was that BBT did not correct hypocapnia, although it was associated with a reduction in minute ventilation [lung capacity]. Consequently, it remains unclear whether hypocapnia and hyperventilation are important contributors to the pathophysiology [cause] of asthma, or merely a consequence of asthma itself.

Overall, the study showed no improvement in the clinical severity of asthma in the BBT group, but there was a significant reduction in the use of β2-agonists. These data indicate that some patients can cope with less medication and suffer no loss of control of their asthma. If this is the case generally, then many patients are taking unnecessary medication, leading to increases in adverse effects and expenses for these drugs. Medical practitioners should review regularly the asthma therapy of their patients and consider dosage reductions (back-titration).

Both the above studies reinforce the need to improve the quality and quantity of evidence that is used to guide healthcare practice. This applies equally to both alternative and orthodox therapies. The increasing recognition of this need has prompted greater emphasis on clinical epidemiology in undergraduate and postgraduate education. The Cochrane Collaboration is an example of an organised approach to the production and dissemination of high quality evidence. It has an Airways Group, which produces systematic reviews of therapy in respiratory disease and includes alternative therapies in its scope.

As demonstrated by the studies of Liu and Douglas and Bowler et al., particular problems in trials of alternative therapy include adequate blinding and the use of an appropriate placebo. Nonetheless, these are crucial elements to obtaining valid results. They require ingenious solutions, as demonstrated recently by the report of a "placebo" acupuncture needle.

Essential in the evaluation of any healthcare intervention is the detection of adverse effects. Compared to the substantial regulation and surveillance of orthodox medicine, the relative lack of regulation for alternative medicine may suggest that it is without adverse effects. That this is not the case was most recently illustrated by reports in the *New England Journal of Medicine* on the direct, indirect and potential harm from alternative medicines, summarised in an accompanying editorial. The risks included delay in the use of scientifically validated therapy, and contamination of traditional or herbal medicines with oestrogenically active chemicals, digitalis, heavy metals and a neurologically active solvent. The need for attention to the safety of alternative medicines has been recognised in Australia.

In summary, alternative therapies should be approached in the same way as some parts of orthodox medicine are evaluated now and how most, if not all, will be assessed in the future. That is, if shown to be effective and safe, they should be part of the range of interventions available to patients. Ineffective or unsafe therapies should be abandoned, and unproven interventions should be evaluated in high quality clinical trials. As proposed in the *New England Journal of Medicine* editorial, it may be time to stop using the terms "orthodox" and "alternative" and to classify health interventions into whether or not they have been shown to do more good than harm in scientifically valid studies - an evidence-based approach to healthcare.


- Michael J Hensley is both Professor of Medicine and Director of Respiratory Medicine, John Hunter Hospital, Newcastle, NSW. Peter G Gibson is Staff Specialist in Respiratory Medicine, and Director, Airways Research Centre, and Conjoint Senior Lecturer, University of Newcastle, Newcastle, NSW.

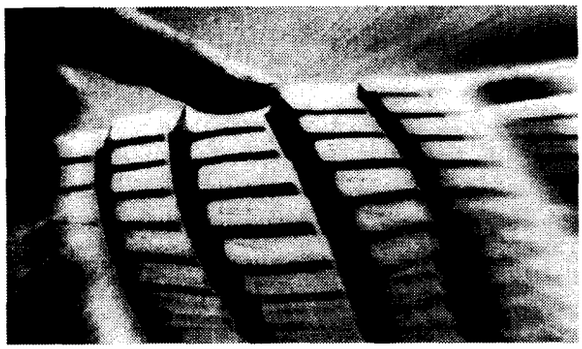


This abridged article is taken from the fully referenced original in the Medical Journal of Australia, 7/21 December 1998. Our thanks to the MJA.

You'd be able to access a copy via your nearest public or university library.

# The internet

By Rosie



There is a way for everyone to surf the internet, and that is to book in at your local library. Most libraries have free internet access and it can be a great way to get confidential information as well as communicate with others who have HCV.

If you know nothing about computers, there is nothing to worry about - it's really easy. The simple rules are to double click on something to open it and click on the x in the top right corner to close it. It's that simple.

So you find a little picture (the icon) labelled either "The Internet" or "Internet Explorer" or "Netscape", and double click on it. When a window opens there are a bunch of little pictures in a row up the top, and you just click on the one labelled "search".

You might get a list of "search engines" to choose from - I really like to use Yahoo. So, say you click on Yahoo. OK, then you get a lot of blurb and ads and stuff, which if you're like me, you'll just ignore. Amongst it all there'll be a little white space that you can type in. Type "Hepatitis C", or "Hepatitis C FAQ" (frequently asked questions).

Once you get your search results, you just have to scroll through them. Click on the blue writing (the web address) on sites that look interesting and it'll take you there. You can find a whole bunch of sites easily that way.

Or rather than use search engines, you can go up to where it says "Address" and type a web address, like these:

Peppermint Patti's homepage is at:
http://members.bellatlantic.net/~clotho
and she has a link to Hepatitis C FAQ.

This is a 70 (or so) page document which I printed out and took to the local health clinic, where I photocopied it and left it for the doctor's information. If you go there on the Internet, you can find your questions and click on the link to get there immediately, it's much easier than leafing through 70 or so pages.

These are addresses of some of my IRC "cyber friends:

Liquidize's homepage is at:
http://www.geocities.com/SouthBeach/4138/?

Mary Jane's homepage is at:
http://www.geocities.com/SouthBeach/Breakers/7277/

DustyDog's homepage is at:
http://home.onestop.net/dustydog

***"Most libraries have free internet access and it can be a great way to .. communicate with other people who have hepatitis C."***

Flowerchild's homepage is at:
http://www.geocities.com/Heartland/Valley/6778/

Liffie's homepage:
http://www.geocities.com/BourbonStreet/Delta/9025/links.html

These people have told the story of their lives, or their lives with hep C at least.

Mary Jane and DustyDog have both given me permission to use their stories, so for those who haven't tried the Internet yet, *Good Liver* has permission to publish their stories in future editions.

For those with access and e-mail, here are the addresses for two mailing lists:

A US based list is at
LISTSERV@MAELSTROM.STJOHNS.EDU
just send an e-mail with the word "Subscribe" in the body of the mail, and nothing else.

And a UK based list is at HEPC@ARIESS.COM
if you just ask Daniel to subscribe you, he will help.

- Abridged with thanks from *Good Liver*, Spring Edition 1998, published by the Hepatitis C Council of Victoria.

# The club

About the only words of comfort I can offer Walter Payton [a famous US footballer] are welcome to the club. You have joined about 11,000 of us in America who are waiting for a liver transplant.

The fact that only half of us will get one this year is the shaky part. The donor rate isn't as good as it should be in this age of enlightenment. A lot of otherwise generous people remain queasy about organ donations. Perhaps you can create a better awareness.

My problem is a little different from yours. I have hepatitis C, the latest boutique disease. Doctors have just begun to track its raging path through the populace. They fear this new epidemic may kill more Americans than AIDS.

Unlike the more common and controllable hepatitis's A and B, ``Hep C'' lurks for years after a viral infection. Its main avenue of transmission is through infected blood. That's why a lot of people affected are drug users who share equipment. Another bunch are the medical workers who intimately contact the blood of others.

That's how I figure I got this disease. I was a medic in the US Army Reserve. We didn't worry much then about blood-borne disease. Now we know better. But for some, it's too late.

Either way - with my hepatitis C or your primary sclerosing cholangitis - our livers have weakened and are dying. Hopefully, we'll get new ones in plenty of time to live full and reasonably normal lives.

But now there is that other factor - the one that truly gives me chills. The worst part of waiting for a liver donation that may save my life is knowing someone else has to die.

I realize this death will not be my fault. I will not have ordered the car wreck, gunshot or fatal plunge to brain death that leaves a victim hopeless of recovery. I know this is simply a statistical matter of numbers. I will go about my business in blissful ignorance, hoping for some anonymous match, anticipating a call night or day.

Is an accident happening now that will change the course of my life as well as the lives of another family? I feel myself careering along a frightful path as two of us race toward a fateful intersection.

I'll admit this whole process leaves me a little scared. This is no simple procedure. There are no guarantees of survival, although the odds are good.

I choose not to worry. Worrying basically gets in the way of important things like being needled by your friends, having them order fried liver when you go out, having them ask you to pick out a handsome, healthy guy whom they can nab and haul to the medical center. If I can't use the liver, they figure maybe I can get the face.

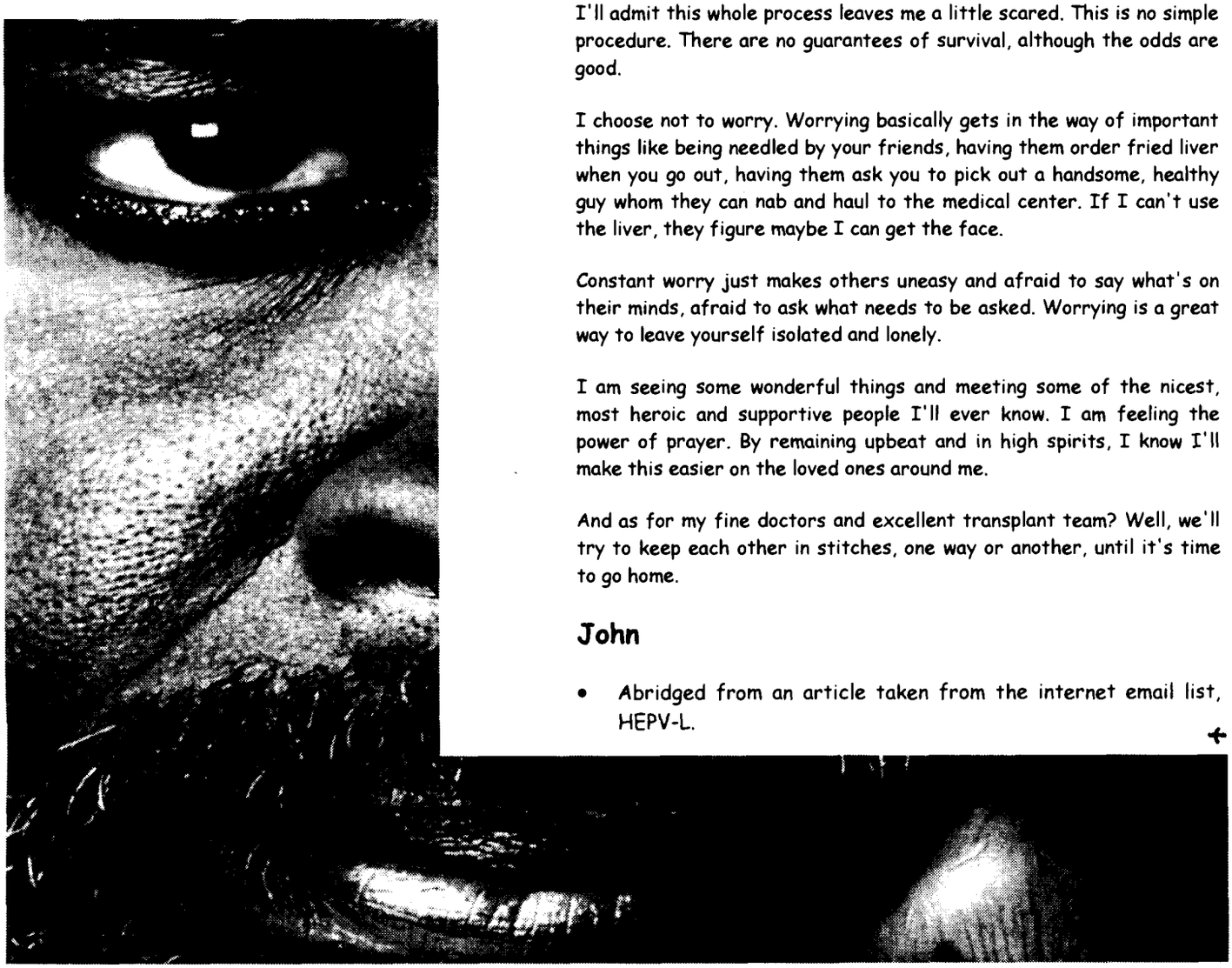
Constant worry just makes others uneasy and afraid to say what's on their minds, afraid to ask what needs to be asked. Worrying is a great way to leave yourself isolated and lonely.

I am seeing some wonderful things and meeting some of the nicest, most heroic and supportive people I'll ever know. I am feeling the power of prayer. By remaining upbeat and in high spirits, I know I'll make this easier on the loved ones around me.

And as for my fine doctors and excellent transplant team? Well, we'll try to keep each other in stitches, one way or another, until it's time to go home.

## John

- Abridged from an article taken from the internet email list, HEPV-L.



(model/s used above)

# Food supplements data base to provide scientific facts

The burgeoning "dietary supplements" industry, with a natural substance to treat nearly every ailment and a store to sell it in nearly every mall, has had severe shortages in one area: facts.

Whether it's ginko biloba to ward off senility or St. Johns Wort for depression, [U.S.] consumers who pushed sales of the herbal remedies industry to $15 billion last year have little information about the products they are swallowing each morning.

Officials of the [U.S.] National Institutes of Health Office of Dietary Supplements on Wednesday unveiled a plan they hope will start changing all that.

A new internet site <http://dietary-supplements.info.nih.gov> will provide the public with "user friendly" access to information from more than 250,000 scientific research reports on the effects of 50 of the most popular dietary supplements.

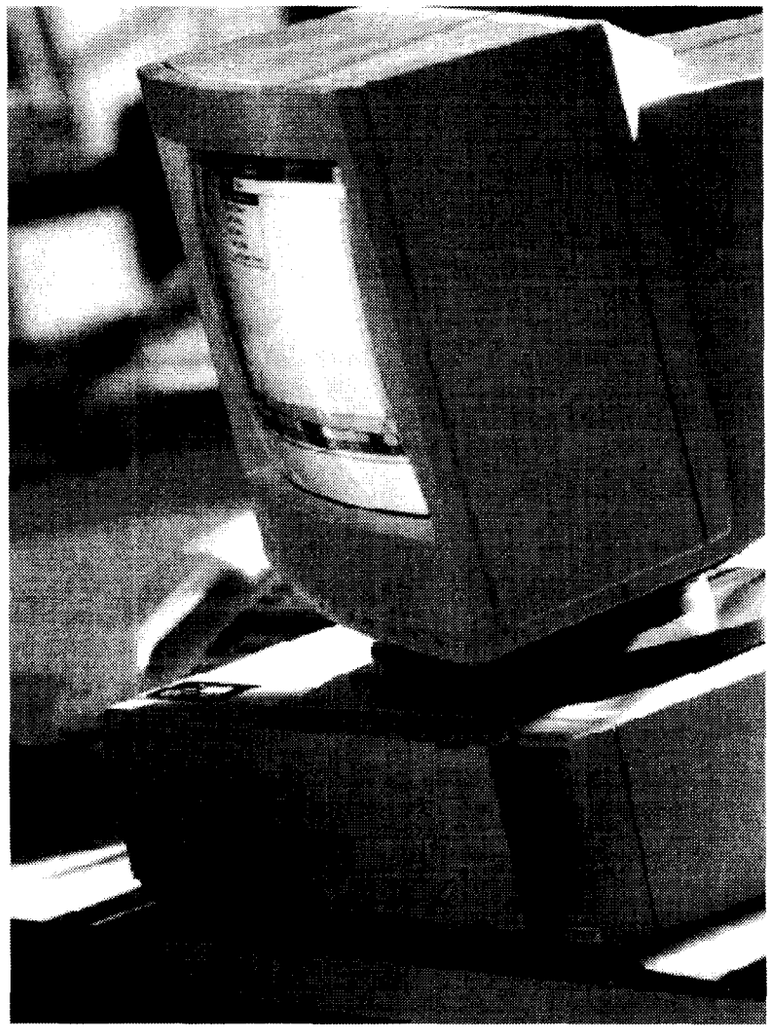
When the site is fully operational, anyone with access to the internet can key in a few words and get a list of the titles and summary abstracts of scientific papers dealing with dietary supplements.

The database was developed with assistance from the [U.S.] Department of Agriculture's National Agricultural Library, said Bernadette M. Marriott, director of the [U.S.] Office of Dietary Supplements.

The database will not provide the full text of scientific articles. Consumers will have to go to a public or university library to find that.

It is acknowledged that some of the abstracts are highly technical, such as a "calcium" find that offers information on "involvement of a guanine-nucleotide-binding protein-mediate mechanism for enhancement of arachidonic acid liberation by phorbol 12-myristate... "

Detailed information is listed as the database will be used not only by consumers but by scientists as well.



The [U.S.] Congress in 1994, under heavy lobbying pressure from the dietary supplements industry, passed a law that greatly restricted the authority of the [U.S.] Food and Drug Administration to regulate the substances.

In the aftermath of that law, sales have exploded, and a spokeswoman for the [U.S.] Council for Responsible Nutrition, an industry group, said sales last year appear to have been between $13 billion and $15 billion, although no one is sure what the figure was.

Many scientists, concerned about the soaring popularity and restricted regulation of dietary substances, have warned that people take them without knowing what they are getting - at times to the exclusion of pharmaceuticals or medical care they may need.

But Annette Dickinson, a vice president of the Council for Responsible Nutrition, said the sales have been driven by accumulating scientific data bringing out the health value of food supplements.

"I think the database will be just one more step toward more information ... about what the scientific basis for these products is, and I think that'll be good for the industry," she said.

- Abridged from an article from *The New York Times Syndicate*. Taken from the internet email list, HEPV-L.

# Looking forward

I was always, as my mother put it, easily led. I'd always been a bit of a party girl, enjoying a drink, smoking some weed, and the occasional acid trip.

I didn't finish my first attempt at my nursing training. I was too young and silly to realise what a chance I had in my hands. With my second attempt, I was determined that this time I was going to get it right! I was 23, and I figured more mature than the last time. My class was a mixture of mature age students, and younger people straight from school.

The first six months was cool. I was getting on well with everyone, from doctors, cleaners, kitchen staff, to my peers. I then embarked on a relationship, that proved to be most dangerous!

This guy was my friend, confidante and generally good mate. We used to drink and play up together, and then he let me in on him shooting up!

I was intrigued, to say the least, but had always told myself that I would draw the line when it came to using heroin and needles. I'd seen too many patients in hospital beds as a result of their dabblings! But that resistance didn't last all that long. Soon enough, I had tried it and surprise, surprise, I liked it!

My friend seemed to have a handle on it and was able to use recreationally, but with me it was a different story. I felt a little obsessed with it and before long I was stealing pethidine and morphine from the hospital. I was interfering with patients scheduled drug regimes - something that has haunted me for a long time now.

Consequently, my second attempt at nursing also failed - and with only 6 months to go!

Anyway, after using for some time, I began to feel unwell. I couldn't stand the thought of meat, and generally wasn't feeling much like food at all. The doctor I saw suggested a liver biopsy, as I was covered in liver spots!

This was in 1982, and the result was "a sub-clinical dose of nonA-nonB Hepatitis". This didn't mean anything much to anyone in those days so I didn't take much notice.

I eventually gave up heroin in 1986, but continued to drink in a most unladylike fashion - you know, blind drunk bingeing - for many years after that.

In 1994, I was settled, or so I thought. I had a loving partner, a good job and a daughter. Some episodes of abdominal pain turned into removal of gall bladder but 12 months later, the pains kept persisting. I asked the surgeon if there was any possibility that I had hep C - he knowing my history and all - to which he replied "I doubt it, but we can check if you like." A positive result being the outcome!

Four years later. Now I find myself in the middle of a very messy breakup. My previously loving partner has not been able to cope with the news. He has been dishing out emotional abuse ever since we found out. He generally denigrates me about my past.

We live in a small rural community, and because I have initiated the break-up (because I couldn't stand his abuse any longer) he is freaking out.

He says he wants to continue with our relationship, but only if I admit to doing things that he has imagined I have done. He threatens me. He says he is going to announce to the whole town my life history! And the worst thing about it is, it will be a very inaccurate account!

I gave up drinking when I found out I had HCV, and he has continued to drink very heavily. I don't go to clubs or pubs where he goes and I don't interfere with his life. But he has decided that he has been very badly done by, and so will smear my name through the gutters in town. And guess what? They will believe him as he is very much one of the locals.

Because I have kept very much to myself since we moved here, no one knows much about me. He wanted it that way, and I was happy to keep it like that. Now, it looks like I'm going to be 'tagged'!

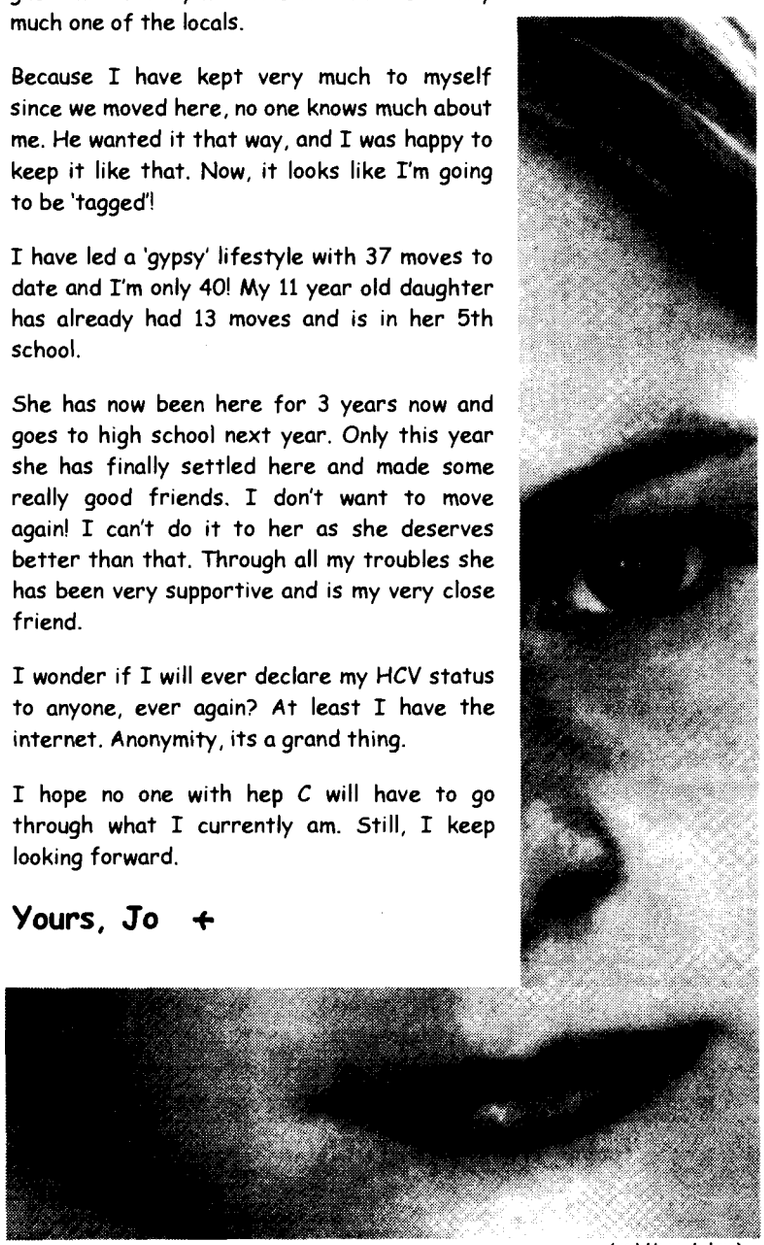
I have led a 'gypsy' lifestyle with 37 moves to date and I'm only 40! My 11 year old daughter has already had 13 moves and is in her 5th school.

She has now been here for 3 years now and goes to high school next year. Only this year she has finally settled here and made some really good friends. I don't want to move again! I can't do it to her as she deserves better than that. Through all my troubles she has been very supportive and is my very close friend.

I wonder if I will ever declare my HCV status to anyone, ever again? At least I have the internet. Anonymity, its a grand thing.

I hope no one with hep C will have to go through what I currently am. Still, I keep looking forward.

**Yours, Jo +**



(model/s used above)

# Pegasys - pegylated interferon drug trial

## Introduction

On 17 January, articles appeared in the *Sun Herald, Sunday Telegraph* and *Brisbane's Courier Mail* and on some television news programs about a new hepatitis C drug, "Pegasys", being trialed in Melbourne, Sydney and Brisbane.

Articles in the papers were misleading and incorrectly reported the results as arising from Australian studies.

## The Pegasys trial

The actual trial was conducted in the United States. Preliminary results from the American trial suggest that Pegasys interferon reduced HCV to undetectable levels in over 75% of patients within 12 weeks of treatment, compared with only 17% of those treated with standard interferon.

"The effect (ie non-detectable levels of HCV) was maintained for 24 weeks following completion of treatment in 37% of those receiving Pegasys, versus 3% on the currently available treatment."

In other words, sustained success with Pegasys could be 37% vs. the claimed 3% on currently available interferon monotherapy.

Many other studies show sustained success rates for interferon monotherapy of between 15% to 40 %.

It is important to note that the US trial is still in its research stages and the findings referred to are preliminary results so far.

## Can I get onto the Australian trial?

In Australia, the treatment therapy is still in its research stages. It's quite likely that trial places are full, but people interested in going on the trial should call the liver clinic of their nearest major hospital.

Please note that in Australia, subject to trial results, it is unlikely that Pegasys will be considered for approval as a treatment therapy for at least another 18 months to 2 years.

## What is pegylated interferon?

"Pegasys" is a drug brand name of "pegylated" interferon. It combines interferon with a sustained release substance (poly-ethylene glycol) that bonds to the interferon molecule and slows down the release of interferon into the body. Therefore, it needs to be injected only once or maybe twice a week.

This gives a smoother, slower and more measured level of interferon release. It is thought that the body is better able to cope with the slower release, hopefully leading to the reduction in side effects. The more optimistic results seen so far are believed to be a result of the slower release of Pegasys compared with standard dose interferon.

## What other pharmaceutical trials and treatments are available?

Combination interferon/ribavirin therapy is also still in a trial phase in Australia (see page 38), but is also unlikely to be available as an approved treatment therapy for between 18 months to 2 years.

The only pharmaceutical treatment currently available under the Pharmaceutical Benefits Scheme (S100) is standard dose interferon monotherapy for 12 months (see page 40).

Some specialists and other doctors are advising HCV positive people considering treatment that they may wish to consider waiting till better treatments have been approved and are available.

## Further information

For further information about hepatitis C, contact the NSW Hepatitis C Telephone Information and Support Service (see page 42).

- Produced with assistance from NSW Health, and Profs Bob Batey and Geoff McCaughan.

# Hepatitis through the ages - part 2

(Continued from Edition 23, p36)

This is our second excerpt of an article that explains the history of hepatitis illnesses, taken with thanks from 'Hepatitis' by Alvin, Virginia and Robert Silverman - part of the 'Diseases and People' series of books, Enslow Publishers Inc, 1994.

## The first pieces of the puzzle

In 1964 Dr. Krugman began another set of experiments that lasted three more years. He fed eleven children a mixture containing blood drawn from a large number of hepatitis victims at Willowbrook. After thirty to sixty days, ten of the eleven had come down with hepatitis. Dr. Krugman drew a blood sample from one of the infected boys and labelled it MS-I.

Six months later the same children were injected with the virus mixture. Within two months some of the children became infected again. The second infection took longer to show up, and it took longer to get over the first oral infection. Dr. Krugman took another sample of blood from the same boy and labelled it MS-2. Now he had two blood samples, MS-I and MS-2, which he believed contained two different viruses that caused hepatitis. The first had been transmitted by mouth (orally) and the second by contaminated blood.

In the third trial, which involved fourteen children, eight children were injected with MS-I, the oral hepatitis infection. Seven of the eight children became infected within a month. All of the other six children became infected as well, even though they had not received any injections. They had caught the virus just from contact with the other seven.

Then fourteen more children were selected; nine were injected with the MS-2 hepatitis infection. In a month and a half seven of the nine became infected, but only two of the five children who hadn't been injected developed hepatitis.

The researchers on the New York University team concluded that there were two different viruses, one that was highly contagious through blood but less contagious by contact. Dr. Krugman hadn't identified the hepatitis viruses, but he did show that they caused two separate diseases. Eventually the MS-I and MS-2 viruses became known as hepatitis A virus (HAV) and hepatitis B virus (HBV), respectively.

## Discovering a way to detect the viruses:

The next piece of the hepatitis puzzle, like many scientific achievements, was discovered partly by chance. Disease researcher Dr. Baruch Blumberg didn't have hepatitis in mind at all when he started his monumental hepatitis research. He was trying to find out why people of different races react differently to disease organisms. Just as humans can have different blood types, he believed that there must be slight differences in our genes that control our immune systems, causing people to react differently to diseases.

Blumberg began collecting blood samples from hundreds of thousands of people around the world. To find genetic differences, he looked for proteins that were found in some blood samples, but not in others. Genes create proteins, so differences in blood proteins are a reflection of genetic differences. Dr. Blumberg decided to test the blood of people who had received many blood transfusions.

When a person receives blood from someone else, there are foreign proteins in the blood. Some of these proteins might prompt the body to build antibodies. The researchers could examine these antibodies to figure out what the foreign proteins were.

In 1963 at the Institute for Cancer Research at Fox Chase Centre in Philadelphia, Dr. Blumberg, working with Dr. Harvey Alter at the National Institutes of Health (NIH), discovered a set of antibodies in a New York haemophiliac's blood that reacted with the blood of an aboriginal Australian. That meant that there must be an antigen (a foreign protein) in the blood of the Australian that prompted antibody production. Blumberg called the protein the Au antigen, for Australia.

Blumberg and Alter tested the blood of people from different areas around the world to see whether the antigen was present in other populations. Although the protein was very rare in the United States, it was more common in blood samples of people from some parts of Africa and from parts of Asia such as the Philippines. Then they found that blood samples from leukemia patients at the University of Pennsylvania's medical centre often contained the Au protein.

The researchers wondered whether the protein might be an indicator of people who were prone to leukemia. They decided to examine the blood of a group of children with Down's syndrome, because these children are 20 to 2000 times more likely to develop leukemia than other children. They found that 30 percent of the Down's syndrome patients in a nearby institution were positive for the Au antigen.

"Until this time all the individuals with Au who had been identified either lived in Australia or some other distant place or were sick with leukemia," Dr. Blumberg says. The researchers wondered what patients with Down's syndrome and leukemia could have in common with an aboriginal Australian.

The mystery began to unravel when James, one of the teenagers with Down's syndrome who had previously tested negative for Au, suddenly tested positive. Tests revealed that James had recently developed hepatitis. It seemed likely that the Au antigen had something to do with hepatitis. Now things started to make sense.

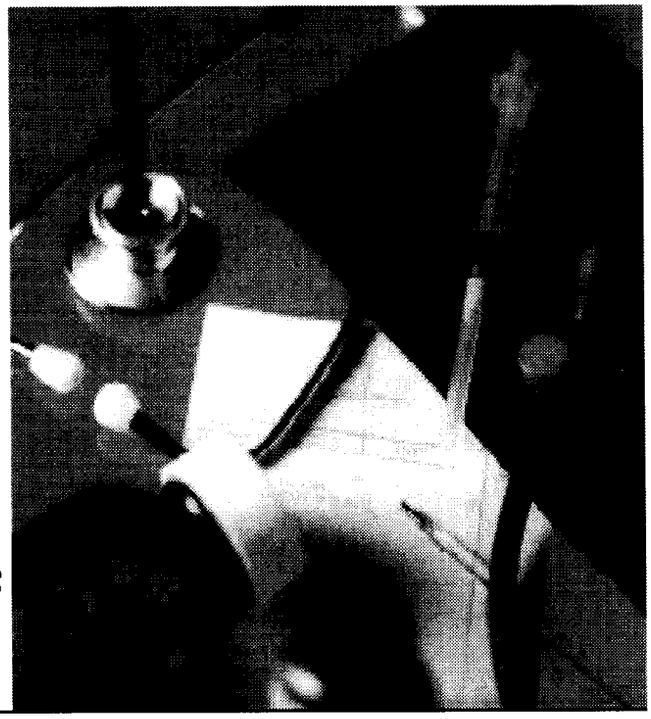
- This article will be continued in our next editions. The various instalments will together, eventually explain the history of scientific research into viral hepatitis. +

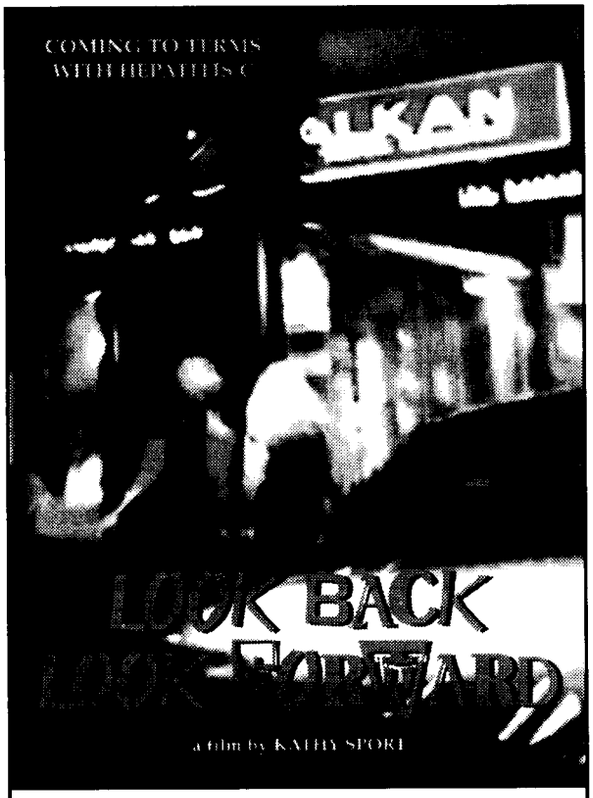
# next edition

## In the next edition we plan to overview:

- the existing drug treatment, interferon,
- emerging therapies currently being trialed, and
- what the future may hold in regard to medical drug treatments.

If you'd like to share your experiences or opinions, please write in!





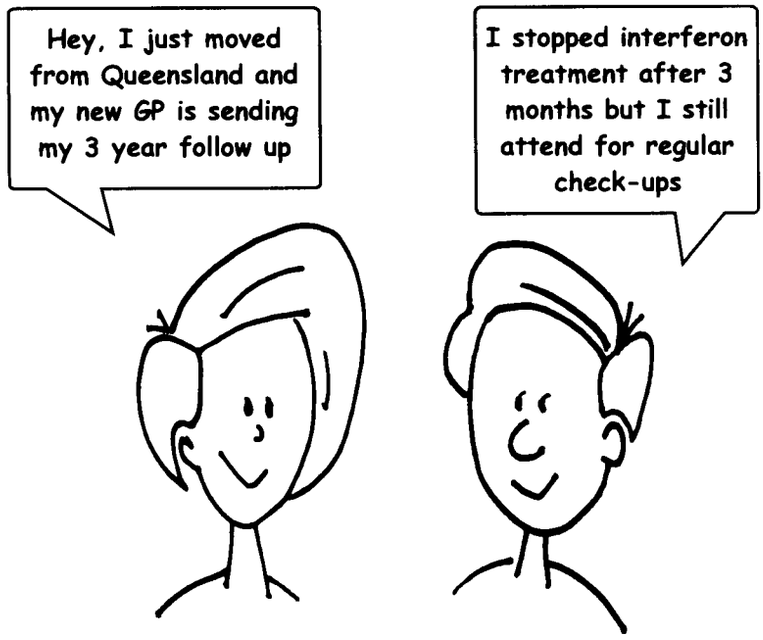

**The new video**

**LOOK BACK LOOK FORWARD**

**is available for loan.**

Please phone or write to the Council office with your postal details and phone number. We'll post it out. All you have to do is pay for the postage when you send the video back to us.

If you're interested in purchasing the video, contact Ronin Films on 02 6248 0851.




**If you've had interferon and don't attend for follow up checks, they won't find out how to improve the treatment. Make sure your treatment centre or GP forward your follow up reports to the Hepatitis C National Database ph. 02 4921 7431 fx. 02 4921 7432**

# Do you think you might have hepatitis C?

To find out more about hepatitis C

call the
NSW Hep C Info
& Support Service

9332 1599
for Sydney callers

1800 803 990
for NSW callers

Above graphic, courtesy of the Hepatitis C Council of Victoria

# Update of hep C treatment trials

| | Aushep 06 | Aushep 07 | Aushep 08 | Nthn Rivers CH100 trial |
|---|---|---|---|---|
| **Who's it for?** | People who've already been on interferon but didn't experience a sustained response. | People who've never tried interferon. | People who've never tried interferon & have genotypes 1 or 4,<br>or, 2 or 3. | People with chronic hep C who live in the Northern Rivers region of NSW. |
| **What's involved** | Group 1: interferon @ 10mu daily for 4 wks, then 5mu 3x weekly for 48 wks. Ribavirin given twice daily.<br>Group 2: interferon @ 10mu daily for 4 wks, then 5mu 3x weekly for 48 wks. Placebo capsules given twice daily. | Group 1: interferon @ 9mu daily for 1 mth, then 3mu 3x weekly for > 1 year.<br>Group 2: interferon @ 6mu daily for 1 mth, then 3mu 3x weekly for > 1 year.<br>Group 3: interferon @ 3mu 3x weekly for > 1 year. | **(Genotypes 1 or 4)**<br>Group 1: interferon @ 5mu daily for 8 wks, then 3mu 3x wkly for 44 weeks; plus ribavirin, daily for 52 wks.<br>Group 2: interferon @ 3mu 3x wkly for 52 wks; plus ribavirin, daily for 52 wks.<br>**(Genotypes 2 or 3)**<br>Group 1: interferon @ 3mu daily for 4 wks, then 3mu 3x wkly for 20 wks; plus ribavirin, daily for 24 wks.<br>Group 2: interferon @ 3mu 3x wkly for 24 wks; plus ribavirin, daily for 24 wks. | Participants will not know whether they are taking CH100 or placebo.<br>GP visits and health status surveys at 0,1,3,6,9 months.<br>LFTs at 0,1,3,6,9 months.<br>PCR genotyping at beginning of trial.<br>PCR viral detection and viral load tests at beginning and at 24 wks.<br>Group 1: CH100 taken 3x daily for 24 wks.<br>Group 2: Placebo (harmless substitute) taken 3x daily for 24 wks. |
| **Where are treatment centres?** | Not applicable as enrolments closed. | Nepean, Wollongong, Concord, St Vincent's, Lismore, RPAH, RNSH, Prince of Wales, Campbelltown | Not yet finalised but will probably include most major hospitals<br>See Aushep 7 (left) for a guide. | Particular GPs practising in the Nthn Rivers area participating in the trial. |
| **Would anything rule me ineligible?** | See Aushep 8 (right). | Having cirrhosis,<br>Previous treatment,<br>Injecting drugs (oral methadone OK),<br>Hep B coinfection. | Having cirrhosis,<br>Previous treatment,<br>Injecting drugs (oral methadone OK),<br>Hep B coinfection,<br>Falling pregnant (women),<br>Conceiving a child (men).<br>People should have already had the following tests done prior to enrolment: 1x PCR viral detection test; 3x LFTs showing elevated ALT; a biopsy result no more than 2 yrs old; a negative HBV test. | People must have 2x positive HCV antibody test results - the 1st done at least 12 months prior - and liver function tests showing ALT levels currently or recently elevated above normal.<br>Other exclusion criteria: current interferon or any herbal treatment, hypertension, pregnancy or breastfeeding, psychotic illness, non-HCV liver disease, HIV/AIDS, injecting drugs, alcohol intake of >70g per wk. |
| **Enrolments still open?**<br>**(ph contacts)** | Enrolments have closed and Aushep 6 is now in progress. | Yes. Contact the liver clinic at your nearest trial centre.<br>See above. | Enrolment will be open soon. Most of the barriers have been overcome but final approval has not yet been received.<br>Currently, people can contact the 'liver clinic' at their nearest major hospital. | Enrolment is still open. People living in the Nthn Rivers area can contact:<br>Nikki Keefe<br>02 6620 7518 (Thurs),<br>Tim Sladden<br>02 6620 7509<br>(other days, Mon-Fri). |

**INject YOurSelF**

**INFecT YouRSelf**

**You**

Can INject without catching Hep C. If you already have Hep C you can avoid reinfecting yourself.

**How?**

CHange the way YOU INject.

**Avoid Hepatitis C When Injecting - Whenever possible try following this guide to avoiding blood contact.**

**The amount of blood needed to infect someone else with the Hep C virus can be so small that you can't even see it.**

**Injecting Gear -** have a new fit, spoon, water, filter, swab and tourniquet

**Clean Your Act Up -** wash your hands with warm soapy water and clean your spoon with a fresh swab

clean the fingers you'll use to pull off a filter with a fresh swab

keep all your injecting gear separate from other people's gear

*(For example; a shared tourniquet could have been touched with (invisibly) bloody fingers or may rub over someone else's injection site, then over yours, sharing blood and hep C)*

**Do it Yourself -** inject yourself - if someone else does inject you, make sure they've washed their hands first

**During and After -** if you get blood on your fingers, go and wash your hands before you touch anything on the table - if someone tells you to pass them something, tell them to wait

if you do touch something by accident, (a cup, fit bin - whatever) let your mates know not to touch it themselves before they hit up.

wash your hands after touching anything that someone else who has just injected may have touched

***Remember***

- use new equipment every time - Your fit, Your water, Your filter, Your swab, Your tourniquet - *It's Your Life!*
- wash your hands with soap and water
- make sure the bench or table where you're injecting is as clean as possible

***Can't be bothered with all that?***

If this all seems too hard, remember that many suggestions are common sense - it's all about avoiding even the smallest amount of blood contact. A bit of preparation, having new injecting gear on hand and thinking it through is all it takes. For more information on local needle & syringe programs, contact ADIS - 9361 2111 (Sydney) or 1800 422 599 (NSW).

Above page taken from the Kirketon Road Centre newsletter. Our thanks for permission to reprint.

# Interferon

is provided through the Pharmaceutical Benefits Scheme (PBS) Section 100 Highly Specialised Drugs Program. To access the drug through this program, people must have:

- Chronic hepatitis proven by liver biopsy (except patients with blood clotting problems).
- A repeatedly positive antibody test.
- Liver function tests (see Ed21, p16) - with elevated ALT readings, three times over a six month period.
- Absence of cirrhosis or other liver disease.
- For women - not currently breastfeeding nor any chance of pregnancy while under treatment.
- No history of significant psychiatric illness.
- Must be able to attend regularly for treatment & follow-up.
- Alcohol use of no more than seven standard drinks a week.

The course of treatment involves giving yourself an injection three times a week for up to twelve months.

The course of treatment must be continuous and excludes re-treatment of non-responders or people who relapsed. Consequently, people eligible for the 12 months course will be new patients. Treatment subsidy is also extended to patients who, after the completion of 6 months therapy, have chosen to continue a further 6 months at their own expense. If their treatment has been continuous, the Commonwealth will subsidise the remainder of the second 6 month period.

If your ALT readings don't come down after three months on interferon, the treatment ceases to become available under the PBS. To continue at your own expense for the remaining nine months, the interferon would cost about $4,500.

# Treatment centres

Interferon is classified as a potentially hazardous drug with possible serious side effects, and accordingly, the treatment is monitored closely.

Treatment centres ideally should have certain minimum facilities before they treat with interferon, including:

- A nurse educator / counsellor for patients.
- 24-hour access to medical advice for patients.
- An established outpatient liver clinic.
- Facilities to perform safe liver biopsy.

Interferon treatment centres for hepatitis C exist across NSW (see below). You should make sure your centre has the minimum facilities listed above.

If you're eligible and have decided on interferon treatment, you'll then need to go to a treatment centre where you will again be briefed on the treatment and its side-effects.

After clinical assessment which may take a couple of weeks, you will be given take-home supplies of the drug.

You'll have to return for regular monitoring and further supplies. After treatment, your condition will be further monitored to determine how successful it was.

# Current treatment centres:

Bankstown-Lidcombe Hospital
Bathurst Base Hospital
Bega District Hospital
Blacktown Hospital
Campbelltown Hospital
Concord Repat. Hospital
Corrections Health Service (Long Bay)
Dubbo Base Hospital
Illawarra Area Hospital
John Hunter Hospital (Newcastle)
Lismore Base Hospital
Liverpool Hospital
Mt Druitt Hospital
Nepean Hospital
Orange Base Hospital
Prince of Wales Hospital
Port Macquarie Base Hospital
Royal North Shore Hospital
Royal Prince Alfred Hospital
St George Hospital
St Vincent's Hospital
Sutherland Hospital
Wagga Wagga Base Hospital
Westmead Hospital

# Side-effects

Interferon makes most people feel ill and some side-effects can be serious. If you are thinking about interferon treatment, seek information about side-effects from doctors who are up to date on hepatitis C, read the Council booklet, *Hepatitis C - what you need to know*, or phone the NSW Hepatitis C Telephone Information & Support Service on 1800 803 990 (NSW callers) or 9332 1599 (Sydney callers).

# Benefits

With twelve months of interferon treatment, it is believed that up to one in three people achieve what is called a 'sustained' remission (see Ed23, p16). This means that the virus seems to be cleared from the person's blood and their liver function returns to normal. Symptoms related to the hepatitis C disappear as well.

***[This information is routinely validated by the Commonwealth Department of Health & Family Services, Pharmaceutical Benefits Branch]***

# Complementary therapies

have been used to treat hepatitis C and its possible symptoms but, to date, there've been few research trials in Australia to check their effectiveness.

Certainly though, many people report positive benefits.

Natural therapists using acupuncture, homoeopathy, herbs or other methods, aim to improve the overall health of their patients.

Good results have been reported by some people using complementary therapies but others have found no observable benefits - and, as with any treatment, it's important to remember that wrongly prescribed medicines can be harmful.

Some people choose complementary therapies as a first or a last resort. Others may not use them at all. Some may use them in conjunction with pharmaceutical drug treatments. Whichever way you choose, you should be fully informed. Ask searching questions of whichever practitioner you go to:

- Is the treatment dangerous if you get the prescription wrong ?
- How have complementary or natural therapies helped people with hepatitis C ?
- What are the side-effects ?
- Is the practitioner a member of a recognised natural therapy organisation ?
- How much experience have they had of working with people with hepatitis C ?
- How have they measured the health outcomes of their therapy ?
- How do they aim to help *you* ?

Remember, you have the right to ask any reasonable question of any health practitioner and expect a satisfactory answer. If you're not satisfied, shop around until you feel comfortable with your practitioner.

# Costs

You cannot claim a rebate from Medicare when you attend a natural therapist. Some private health insurance schemes cover some complementary therapies. It pays to ask your natural therapist about money before you visit them. Many will come to arrangements about payment - perhaps a discounted fee?

# Choosing a practitioner

If you decide to use complementary therapies, it's vital that you see a practitioner who is properly qualified, knowledgeable and well-experienced in working with people who have hepatitis C.

It's also advisable to continue seeing your regular doctor and/or specialist. Talk to them and your natural therapist about the treatment options that you are considering and continue to have your liver function tests done.

It's best if your doctor, specialist and natural therapist are able to consult directly with one another. If a natural therapist suggests that you stop seeing your medical specialist or doctor, or stop a course of pharmaceutical medicine, *you may want to consider changing your natural therapist.*

# Healthy herbs?

The use of herbal medicines to treat a wide range of conditions is being promoted world-wide by the World Health Organisation.

In regard to hepatitis, around 20 years of clinical research in Europe has already been completed on the herb *milk thistle*, which some people are using as a liver tonic here in Australia. In Germany, a standardised extract has been approved for treatment of various liver disorders including cirrhosis. There are no known adverse side-effects associated with short- or long-term use of this herb.

A recent Australian trial of one particular Chinese herbal preparation has shown positive benefits and few side-effects (see edition 15.)

# Want more information?

Contact any of the following organisations:

| | |
|---|---|
| Australian Acupuncture Association | 1800 025 334 |
| Australian Homeopathic Association | 02 9879 0049 |
| Australian Natural Therapists Association | 1800 817 577 |
| Australian Traditional Medicine Society | 02 9809 6800 |
| Association of Remedial Masseurs | 02 9807 4769 |
| Homeopathic Association of NSW | 02 9247 8500 |
| National Herbalists Association of Australia | 02 9211 6437 |
| Register of Traditional Chinese Medicine | 02 9660 7708 |
| Australian College of Acupuncturists | 02 4677 2358 |
| NSW Association of Chinese Medicine | 02 9212 2498 |
| Australian Traditional Chinese Medicine Assoc. | 02 9699 1090 |

# NSW Hep C Telephone Info and Support Service

For confidential and anonymous information and emotional support you can phone the NSW Hepatitis C Telephone Information and Support Line.

9332 1599 (Sydney callers)
1800 803 990 (NSW callers)

The service gives you the opportunity to chat with trained phone workers and discuss those issues important to you. It also provides referral to local healthcare and support services.

# Sexual health clinics

Although hepatitis C is not classified as a sexually transmitted disease, staff at these clinics can offer a range of services including pre- and post-test counselling, antibody blood tests, general counselling and primary healthcare (the type of service that GPs provide). They are listed in your local phone book under 'sexual health clinics'.

If you are concerned about confidentiality, these clinics do not need your surname or Medicare card and keep all medical records private.

# Community centres

Community Health and Neighbourhood Centres exist in most towns and suburbs. They provide different services, including counselling, crisis support and information on local health and welfare agencies. Some Neighbourhood Centres run a range of support and discussion groups and activities that may range from archery to yoga.

Community Health Centres can be found by looking in your White Pages under 'Community Health Centres'. Neighbourhood Centres can be found by phoning your Local Council.

# Local support services

There are few local hepatitis C specific support services. This isn't because of lack of need but because there have been inadequate resources to develop them, or integrate other appropriate services. So where does this leave you?

For particular assistance, whether it's help with the kids, housing, finances or home shopping, look in the White Pages telephone book. In the front, you'll find a whole range of services that are mostly aimed at the general community.

**Following is a list of healthcare workers in your local region who can possibly refer you to local hepatitis C services:**

| | | |
|---|---|---|
| Mid Nth Coast | Robert Baldwin | 02 6583 0750 |
| Western NSW | Scott Davis | 02 6881 2215 |
| Hunter | Marilyn Bliss | 02 4924 6477 |
| Mid West NSW | Dave Brackenreg | 02 6332 8576 |
| Southern NSW | Geetha Isaac-Toua | 02 4827 3328 |
| South West NSW | Dalton Dupuy | 02 6058 1700 |
| Nthn Rivers | Wendi Evans | 02 6620 7505 |
| | Linda Blackmore | 02 6688 2088 |
| New England | Karin Ficher | 02 6766 2288 |
| Central Coast | Karen Nairn | 02 4320 3399 |
| Illawarra | Brian O'Neill | 02 4228 8211 |
| Wentworth area | Elizabeth O'Neill | 02 4724 3877 |
| Western Sydney | Chris O'Reilly | 9840 4105 |
| | Rob Wilkins | 9840 4110 |
| Nthn Sydney | Bernie Coates | 9926 6717 |
| Central Sydney | Peter Todaro | 9515 9600 |
| | Jan Pritchard-Jones | 9515 8643 |
| Far West NSW | Darriea Turley | 08 8080 1511 |
| SE Sydney | David Willock | 9382 8370 |
| Sth Wst Sydney | James Mabbutt | 9827 8033 |
| | Laura Baird | 9828 5944 |

# One-to-one counselling

Some people with hepatitis C may want to talk to a specialist counsellor who can provide special support or therapy when they have specific problems they're having difficulty dealing with.

Some situations where this may be useful include where someone has excessive anxiety about the outcome of their hepatitis C, or if they have a particular problem that impacts on their hepatitis C infection.

To find out more, speak to your GP, or contact your local sexual health clinic, Community Health and Neighbourhood Centres, or the NSW Hepatitis C Telephone Information & Support Service.

TRAIDS - the Transfusion Related AIDS & Infectious Diseases Service - was originally set up to provide counselling and support to people who contracted HIV through contaminated blood products. TRAIDS now also provides services to any people with HCV.

# Family counselling

If hepatitis C is impacting on your family relationships, it may be wise to seek family or relationship counselling.

To find out more, speak to your GP; look in the Yellow Pages under 'counselling'; contact Family Planning or your local Community Health or Neighbourhood Centre; or phone the NSW Hepatitis C Telephone Information & Support Service (see above, top left).

# Stop Press

## Awareness campaign

We believe there are plans to run a state-wide community awareness program about hepatitis C.

We will report in detail within our next edition of *The Hep C Review.*

## Do you own a newsagency or work at one?

If so, we'd greatly appreciate it if you could pass on to us some of the posters used to advertise glossy magazines - once they are dated and no longer wanted.

If you are able to help out, please give Paul a call on 9332 1853 and we'll arrange everything.

## Were you aware?

If you have picked up this magazine at a liver clinic or other agency you probably aren't aware that the Hepatitis C Council of NSW is an independent membership organisation - a bit like a union or cooperative.

We do not aim to make a profit - our brief is simply to provide HCV info and support services to a whole range of people.

Being an independent organisation, we do rely on membership fees.

If you are not currently a member of the Council, please consider joining up. You'll be directly helping us provide services to people affected by HCV - such as production of this magazine.

**Except for videos and brochures, these resources are available free of charge.**

Videos are borrowed for two weeks at a time and will only cost you the return postage. Phone or write and tell us what you'd like - but please do not send any payment for videos - just pay for the return postage when you post them back to us.

**Eds 1-8 back issue pack** - various topics / historical interest

**Ed 9** - Chiron's patent / living with grief

**Ed 10** - natural therapies

**Ed 11** - genome subtypes / life insurance / Terrigal symposium

**Ed 12** - drug law reform / HCV fatigue / women & HCV

**Ed 13** - HCV & prisons / 94-95 annual report

**Ed 14** - discrimination / drug law reform / DSS / clinical trials

**Ed 15** - partying safe / informed consent / stress / Nat AIDS strategy

**Ed 16** - diet & nutrition / DSP changes / IDU & hep C councils

**Ed 17** - study grants / HCV & relationships / Australasian conference

**Ed 18** - Parliamentary Inquiry / HCV & IDU / safe disposal

**Ed 19** - notifications / diagnosis / understanding research

**Ed 20** - PCR / biopsy / treatments / transplant / tattooing

**Ed 21** - legal issues / liver function tests / sexual transmission

**Ed 22** - living with chronic illness / painkillers & HCV / alcohol & HCV

**Ed 23** - The Neglected Epidemic / overseas update / genotypes

***Hepatitis C - a brief introduction*** - (brochure @ $5 per 100)

***Hepatitis C - what you need to know*** - (booklet, single copies free)

**Video 1** - ***Interferon / HCV & women*** - (you pay return postage)

**Video 2** - ***homeopathy / herbalism*** - (you pay return postage)

**Video 4** - ***hepatitis C / the liver*** - (you pay return postage)

***Look Back Look Forward*** - video (you pay return postage)

***Research Pack 1*** - epidemiology / prevention / serology / diagnosis

***Research Pack 2*** - overview / National Action Plan

***Research Pack 3*** - 1994 NHMRC Hepatitis C Report

***Research Pack 4*** - surveillance / post-transfusion HCV / herbalism

***Research Pack 5*** - AHMAC / NSW Taskforce Report

***Research Pack 6*** - prisons / treatment / IDU / PCR

**We have an abridged version of our booklet, *Hepatitis C What you need to know*, on a website. Look for it at..**
http://www.span.com.au/hepatitis_c/info.html

# *Membership form*

Please complete as much of this form as possible. Our policy is to respect your privacy. All details on this form are treated in the strictest confidence and all communication is carried out discreetly.

**Please return this form with your cheque, money order or credit card details to:**

**Hepatitis C Council of NSW**
**PO Box 432 DARLINGHURST NSW 2010**

Please make cheques out to *Hepatitis C Council of NSW.*

**1. Please complete either a, b or c.**

**a. For people affected by hep C, or other interested people.**

| | | | |
|---|---|---|---|
| Name | | | |
| Postal address | | | |
| Suburb / Town | | | |
| State | | Postcode | |
| hm phone | | Wk phone | |

**b. For individual healthcare or welfare professionals.**

| | | | |
|---|---|---|---|
| Name | | | |
| Occupation | | | |
| Postal address | | | |
| | | | |
| Wk phone | | Wk fax | |
| Mobile phone | | Email | |

**c. For agencies, companies and organisations.**

| | | | |
|---|---|---|---|
| Organisational name | | | |
| Contact person | | | |
| Position | | | |
| Postal address | | | |
| | | | |
| Wk phone | | Wk fax | |
| Mobile phone | | Email | |

**2. If you can help with any of the activities listed below, please tick the following boxes.**

| | |
|---|---|
| Admin and office work? | |
| Other? | |

**3. Is this a renewal, or are you a new member?**

| | | | |
|---|---|---|---|
| Renewal | | New member | |

**4. Please circle one membership fee box.**

All memberships expire on 1 March each year and should be renewed as soon as possible after this date.

Our range of fees allows for people with no real form of income (eg. prisoners) to pay a zero fee. We suggest people on government benefits could pay the concessional fee.

| | | | |
|---|---|---|---|
| Waged | $25 | Professional healthcare worker | $40 |
| Concession | $10 | Community-based organisation | $50 |
| Zero Fee | $0 | Public/Private sector organisation | $70 |

**5. Separate donations are gratefully accepted by the Council.**

If you make a separate donation, please record the amount here. $

**6. If paying by credit card, please complete this section.**

Card type (please circle): MasterCard | Visa | Bankcard

Card number

Expiry date: month ____ year 19____

Cardholder's signature

Cardholder's full name

**7. Do you require us to send your receipt?** Membership fees are not normally tax deductible. To reduce postage costs, receipts are not normally sent. If you want us to send your receipt, please tick here. →

**8. Declaration.** I accept the objects and rules of the Hepatitis C Council of NSW and apply for membership of the Council.

Signed Dated

| This section is for office use only staff initials | Date received | $ received | Receipt no. | Date entered | Member no. | Info pack |
|---|---|---|---|---|---|---|
| | | | | | | |
| | | | | | | |