The Hep C Review

Autumn / Winter Edition June 1999 Edition 25

National review highlights need for urgent action

Hepatitis C treatment, care, support and prevention mechanisms remain under resourced, a major national study has reported.

Additional funding is needed to boost the capacity of liver clinics offering treatment services. Also highlighted is the need for improved liaison between GPs and healthcare clinics leading to better testing, counselling and healthcare services for people with HCV.

Improved education and training for doctors and healthcare workers are other key recommendations of the report.

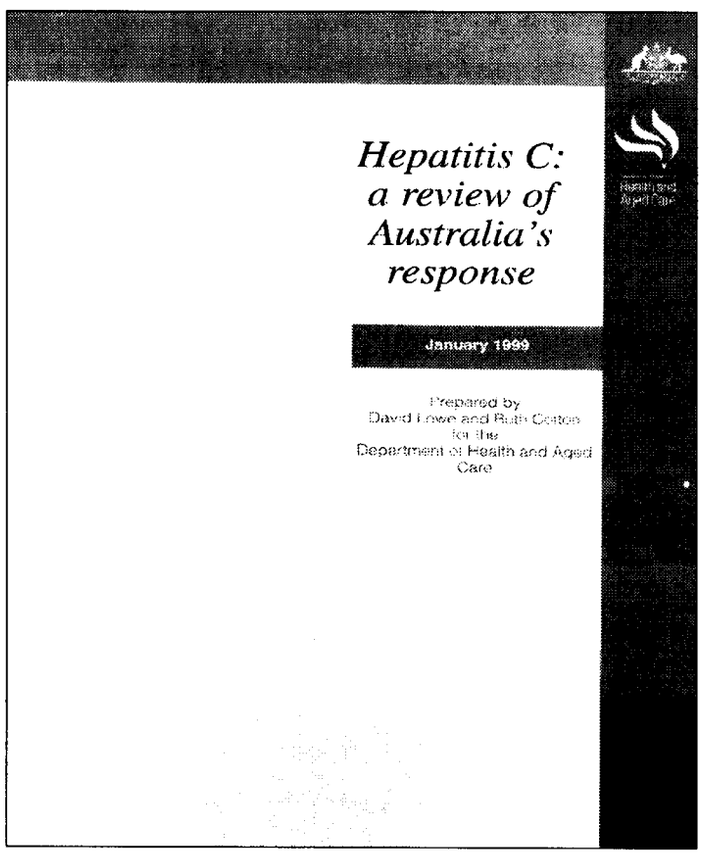
To reduce ongoing spread of HCV, programs are suggested that aim to make injecting of illicit drugs safer, and reduce the number of people who inject illicit drugs.

These represent but a few of the comprehensive range of recommendations contained in the recently released report, *Hepatitis C: a review of Australia's response*. Coming on the tail of the landmark 1998 NSW report, *Hepatitis C, the neglected epidemic*, the national review has been welcomed by the Hepatitis C Council of NSW.

In providing an overview of Australia's response to HCV, the report lists several factors that have heightened the need for further action. These include:

- a growing understanding of the significance of HCV's impact
- more effective advocacy from community-based and professional groups
- more effective leadership giving HCV a greater prominence in national policy making - resulting from HCV's inclusion under the ANCARD umbrella (Australian National Council on AIDS & Related Diseases)
- increased commitment, on the part of governments and public health officials, to tackling the problem.

Despite these factors, the report highlights serious challenges within Australia's response yet to be resolved:



- improving treatment and care for people with HCV
- reducing the number of new HCV infections
- 'getting the research right'
- extending partnerships between those involved
- clarifying structures, roles and responsibilities.

Certainly, this report lends weight to the argument for a comprehensive, stand-alone, top-priority, national hepatitis C strategy - one that details action planning at all levels of government, medical profession and community, and establishes mechanisms to monitor and assess ongoing progress. For more information, see page 18.

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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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Treatment progress

There has been a lot of discussion about new treatments emerging for the treatment of hep C.

In November last year the Standing Committee on Social Issues published the report, *Hepatitis C: the neglected epidemic*. It found there was an estimated 100,000 people with HCV in NSW alone, yet there are only a small number of people accessing pharmaceutical treatment. The report identifies a number of reasons limiting numbers of people accessing treatment - one of which relates to the effectiveness of current therapies.

So what is available, what is on its way and what are the issues associated with these new therapies?

Interferon

Until recently, interferon monotherapy has been the only conventional treatment available for the treatment of hep C. It has'nt been an appealing option for many as it has been limited in its effectiveness (10-20% long-term response), side effects exist and there are a number of criteria that must be fulfilled to get access to government-funded treatment.

Rebetron Combination Therapy

Earlier this year both the American Food & Drug Administration and the European Medicine Evaluation Agency granted licence for Rebetron, a new treatment for hepatitis C. This therapy involves a combination of interferon injections and ribavirin tablets. Ribavirin has been around for some time, used for treating other medical illnesses, but only in the past couple of years has it been researched in a combination basis for treating hepatitis C.

Two studies published in the November 1998 edition of *The New England Journal of Medicine* showed that treatment with Rebetron was capable of achieving a sustained loss of the hepatitis C virus.

The first study involved people previously untreated. It showed that significantly more of these people had undetectable HCV levels six months after combination treatment (38%) compared with people receiving interferon alone (13%).

The second study involved people who had previously been treated with interferon but had relapsed. Of these people, 49% had undetectable levels of HCV six months after combination treatment compared with 13% of those people in the study who received interferon alone.

These response rates sound great compared to the old figures for interferon monotherapy when it came on the market several years ago, but how will combination therapy make you feel?

There are a number of side-effects associated with combination therapy - those normally associated with interferon, and those of ribavirin (most significantly, a risk of birth defects making adequate contraception a prerequisite for combination therapy).

Pegylated interferon

An article was recently published in newspapers trumpeting another new type of interferon under study called Pegasys. Through the process of pegylation - used with various other medications - interferon molecules are coated to make them more slowly broken down in the body. It is expected that PEG-interferon will only need to be given once a week rather than the current three times weekly.

This treatment has not been approved for use in any country in the world as yet. Trials are ongoing and the initial results are thought to be promising although further research is still needed. Some Australian hospitals are involved in the world-wide trials but it could be 2-3 years before PEG-interferons will be approved and reimbursed for use here. Australian trials of PEG-interferon used in combination with ribavirin are also proposed.

Complementary therapies

There are a few hospitals investigating the possible benefits of conventional medicines used with alternative therapies. Studies are ongoing and it will be some time before results are available.

Options

As with most diseases there are always new treatments emerging. The question for people affected is how long does it take before such treatments are approved for marketing and made available under the Pharmaceutical Benefits Scheme (PBS)? The question for our health authorities is do we opt for the best treatment available now or do we wait and see what else is to come?

Research indicates that the earlier that hepatitis C is treated, the greater is the chance of successfully responding to treatment and clearing the virus. There are also fewer disease complications if hepatitis C is treated early.

A treatment decision is for us, as individuals, to take. We need to find out as much as we can, asking our specialists to explain treatment options and consequences - and access to the emerging combination therapy. Currently only interferon is subsidised through the PBS. People can access ribavirin through trials or purchase it via mailorder although quality may not be 100%. Here in Australia some people may be able to obtain the treatment free through compassionate access programs offered by drug manufacturers via existing treatment centres. It is worrying to note that people who currently inject drugs are not eligible within such programs.

The Hepatitis C Council of NSW will continue to press for timely and considered decision-making by health bureaucrats on new evolving treatments, and where appropriate, access to such treatments for all people affected.

Fitpack safety 1

I write regarding the letter to *The Hep C Review* (Worried, March 1999) concerning the possibility of contamination occurring to sterile syringes when returning used syringes into the FITPACK® (five pack) personal sharps container.

Community concerns regarding FITPACK® container products are taken very seriously by ASP Plastics Pty Ltd (the manufacturing company of FITPACK® products) and DISPOSA-SAFE the primary distribution company for FITPACK® products.

Whilst our Research and Development Team is conducting a detailed evaluation of the claim, our initial investigation suggests:

1. There is no feasible way of "accidentally" breaking the FITPACK® container as reported. Independent tests have shown that only excessive force will cause any damage.

2. The risk of cross-contamination is reduced by:

   a) washing hands or swabbing fingers before and after the injection procedure;

   b) not purposefully bending the needle prior to disposal, and

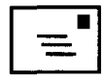
   c) when in the company of others, re-capping your own syringe for disposal. Never, ever re-cap anyone else's syringe.

3. As all new syringes are hermetically sealed and capped there is no possibility of any contamination occurring to the sterile injection equipment itself.

We encourage unencumbered community feedback and debate on the performance of FITPACK® containers to quantify the existing assurance and reliability of our products. In turn, we will strive to acknowledge and address any concerns brought to our attention by end product users or affected communities.

Thank you for drawing our attention to the matter. The FITPACK® R&D Team and our Quality Assurance Officers are duly looking into your concerns. However, following our initial investigations it is highly improbable cross-contamination could occur.

Matt Toomey
Disposa-safe



Fitpack safety 2

I am writing in reply to the letter to *The Hep C Review* (Worried, March 1999) regarding use of the "Fitpack" for dispensing and disposing of needles and syringes through the NSW Needle and Syringe Program (NSP), and the concern that there may be a possibility of cross-contamination of needles and syringes contained in them.

The "Fitpack" container is currently the safest and most reliable means of dispensing and disposing needles and syringes through the NSW NSP. Advice from infection control officers of the NSW Health Department indicates that there is negligible health risk posed to users because of the design of the "Fitpack" container.

Any potential risk may be further reduced or eliminated by exercising care and maintaining hygiene when handling any equipment used to inject, such as by washing hands and injecting sites, keeping the shaft and tip of the needle out of contact with fingers, by not bending or attempting to break the needle before placing it back into the "Fitpack", and by recapping your own needle after use before returning it to the container.

I hope that I have been able to clarify the matter for readers of *The Hep C Review.*

Ross O'Donoughue
Director, Health Protection
NSW Health Department

The Samaritans

We are an informal emailing group, open to all, made up of people who love having the opportunity to help others.

We offer our help by sending supportive emails, snail-mail cards, prayers and by sending the occasional surprise gift to other people going through particularly rough times.

Being a Samaritan provides each of us with comfort and healing of our own as we reach out to our fellow hepatitis friends.

If you are interested in more information, or would like to become a member, please contact me privately at <pat@gofast.net>

Hugs to all - Pat

Inside news

Just thought I'd write a short note to express my appreciation for my free membership to the Hep C Council NSW.

As an inmate of Goulburn Correctional Centre, sending money out, even if I had it, is very difficult and involves many forms, requests etc.

The info in *The Hep C Review* has been invaluable to my understanding of my condition, although luckily for me I so far haven't noticed any obvious ill effects, apart from some fatigue and the occasional stomach ache. This could be stress and the quality of Goulburn tap water that often turns brown as tea!

There still seems to be much misinformation amongst inmates. Simple info in prison newsletters which we occasionally get would help. One printed here in Goulburn is called *INSIDE STORY* made by the education people here at GCC.

I've passed on the brochure order forms to the relevant people here, hopefully they'll use them.

Thanks, 'Alfie'

Thanks

I have been so grateful for all your great support with my hep C. As a single parent and unable to work, I feel upset not being able to donate money for my membership this month. My financial situation is not good.

Due to my hep C my husband left me and my son. I am going through the courts at the moment.

I thank you all very much for all the support you have given and continue to provide. Through all, I have been helped to accept the hep C I received through a blood transfusion in 1980 or 1986 which I was given after major surgery.

I am very self-conscious of all hygiene. I protect my son, he has all of his own eating utensils, drinking cup etc. I do this only because I do not want him to be using things I use.

I cannot tell him I have hep C as he is only 12 years old, but he is a great kid who supports me when I feel sick. I have been taking CH100 which has made a great change in my liver test. My health has greatly improved. I am not so tired, (but not able to sleep) nauseated, cranky and moody.

I find the diet not bad and have been following it as advised. I have put on heaps of weight since 1996; from 42kg to now 53kg. My appetite is back to normal I feel stronger and happier within myself. I seem to handle things from a different angle and not nag all the time.

Many thanks to all at Hep C Council for all your great support.

Sincerely yours, 'Sandra'

[Thanks for your feedback, Sandra. It's probably worth highlighting that there's only a rare chance of transmission in the home. Certainly, we wouldn't recommend the use of separate cutlery or crockery. Hep C isn't transmitted by saliva and for transmission to occur, HCV blood has to enter someone else's bloodstream. We suggest, though, it's a good idea for everybody (not just those who know they have HCV) to not share items that could involve transfer of blood, ie. razors & toothbrushes - Ed.]

Report arrives

I do apologise for my late payment, I honestly forgot so thank you for reminding me.

I am pleased to say I received the book (*Hepatitis C. The Neglected Epidemic*) from the State Parliament, so all our writing to the Social Issues Committee has not been in vain, let's hope they follow through on this to help cope with this worrying disease.

Regards, 'Impressed'

Just a short hello

I had a blood transfusion in 1998 and was unlucky as it contained the hep C virus.

I am now in a permanent state of fatigue and am not enjoying it! I have a digestion problem but with a fat-free diet I manage this condition more or less.

I am lucky that I have no pain but I do get depressed and weepy at times. I am also lucky to have a loving and patient husband.

I always look forward to *The Hep C Review* and read it as soon as it is delivered.

Kind regards, Margaret

Current and emerging drug therapies

Our Council was born out of a patient support group, begun back in 1991 - initiated both in response to the needs of people involved in the first Australian interferon trials, and because of the lack of any information or support for people affected by HCV.

The initial success of interferon in those early trials was not great and it has not improved greatly since then. The biggest news for us all has been the development of our first combination therapy - interferon & ribavirin.

Recent studies point to an improved response rate for the combo therapy and, hopefully, treatment options will continue to expand and improve.

In this edition of *The Hep C Review* we've run a general focus on current and emerging drug therapies for hepatitis C. Although we planned to provide as much information as possible, our ability to cover all aspects of current and emerging therapies is limited.

We hope that our range of articles and news items on current and emerging drug therapies meets your information needs. Should Edition 25 fail to do this, we hope that it provides discussion points and signposts where you can find further, more detailed, information.

Gene expert tips cure for haemophilia

By Mary-Anne Toy

Doctors will soon be able to cure haemophilia by injecting the missing blood-clotting gene into patients, a leading US expert said yesterday.

Dr Richard Samulski told the inaugural gene therapy conference in Melbourne that after years of hype, gene therapy was close to fulfilling its early promise of treating the underlying causes of genetic disease.

"I am very confident that within a year or so we will see diseases such as haemophilia treatable in patients in a same-day procedure," said Dr Samulski, of the Gene Therapy Centre at the University of North Carolina.

People with haemophilia, who miss one or more blood-clotting genes which can cause them to bleed to death, have been treated by intravenous infusion of clotting factor (produced from donated blood) since the late 1970s. It is hoped gene therapy will help the body create its own clotting factor.

Dr Samulski said there was an application before the US Food and Drug Administration for the first trial of gene therapy in humans. It will be aimed at treating the underlying cause of haemophilia B and should begin within six to 12 months.

While haemophilia B affects about 1,600 people in Australia (just under one-third being children), the mechanism of delivering the gene into the body could be used for other diseases.

Professor Bob Williamson of the Murdoch Institute, the organiser of the conference at the Royal Children's Hospital, said the meeting also would address ethical questions relating to the use of the technology.

- Taken with thanks from the SMH 23/2/99.

Federal funding announcement

Over $12 million was allocated for hepatitis C within the federal budget, recently tabled in parliament by treasurer, Peter Costello.

Reflecting the federal health minister, Michael Wooldridge's, commitment to addressing Australia's hepatitis C epidemic, the money is being provided to lower the current rate of HCV transmission. It is planned this will involve provision of improved education, prevention and health maintenance for those already having hepatitis C and those at risk of becoming infected.

The initiative also contains provision for commissioning of research which will help guide key elements of the national HCV response - epidemiology; social and behavioural factors; and education and prevention programs.

Totalling $12.4 million, the funding will be split into $1.5 million for 99/00 (the upcoming financial year); $3.6 million for 00/01; $3.6 million for 01/02; and $3.7 million for the 02/03 financial year.

Hepatitis C organisations and workers, Australia-wide, have welcomed the funding seeing it at as a key leadership initiative from Australia's foremost health authority.

NSW Council grant increase

A significant increase in ongoing funding from our primary funder, NSW Health, was recently secured by the Hepatitis C Council of NSW.

Coming shortly after the recent state election, the increased resources will enable the appointment of three new staff workers: a second *Hep C Helpline* project worker, a community and policy development officer and an administrative/finance officer.

The increase has led to the Council relocating to bigger offices within our current building in Surry Hills, Sydney, and will enable us to both consolidate, improve and expand our existing services.

The increased funding is great news for the Council and is the most significant funding milestone since an earlier funding increase in 1995.

Anger over virus funding rivalry

By Sandra McKay

The Victorian State Government has been accused of pitting groups seeking funding to combat the HIV and hepatitis C viruses against each other.

In a damning draft report obtained by *The Age*, a Commonwealth AIDS advisory group says a shift in priorities from fighting AIDS to hepatitis C has created "an implied sense of competition" between health workers which is now "verging on antagonism".

The Australian National Council on AIDS and Related Diseases (ANCARD), which is reviewing HIV/AIDS strategies for the Federal Government, said the partnership between healthcare workers and the Victorian Department of Human Services was troubled and being undermined by the contest for funding.

For the first time, the state has pooled the finances for the blood-borne viruses, and has begun rationing free condoms to free up funds for needle & syringe programs. Hepatitis C is usually transmitted by an injection of an illicit drug or blood transfusion, while HIV is more commonly sexually transmitted.

The president of the Victorian AIDS Council, Mr Joseph O'Reilly, who has raised concerns in meetings with the Commonwealth's ministerial advisory committee on AIDS, said the situation was crazy.

He said "public health in Victoria would not be served by promoting competition among related diseases."

"Sure HCV needs resourcing, but it shouldn't occur at the expense of another blood-borne virus. Eternal vigilance is the price of preventing a widespread epidemic," he said.

"Equally one technology, namely condoms, shouldn't be put ahead of another, clean needles, as an either/or situation."

The Hepatitis C Council of Victoria was also critical of the State Government's approach.

"The two viruses have actually been held up against each other and it's become an absolute struggle for funding," said the council's coordinator, Ms Jill Meade.

"They're trying to deal with two viruses with one sum of money [and] we're looking at a lot of potential outbreaks because of this inadequate response."

The ANCARD review of the national HIV strategy, to be completed by the end of the year, found that the number of newly diagnosed HIV cases in Victoria had plateaued to 373 cases in 1996-97. It said public health in Victoria would not be served by promoting competition among related diseases.

Victoria had 226 cases of AIDS in 1996-97, representing 20.5 per cent of the national total. Numerically, hepatitis C was a bigger problem, with 200,000 people infected nationally. New infections were growing by 11,000 a year, Ms Meade said.

"But I think it's really very dangerous to say we no longer have to worry about HIV/AIDS, because it is cost-cutting initiatives like cutting condoms that will only put HIV further up the agenda again," she said.

The ANCARD report said the state's view that there was a need to reorganise public resources in favour of hepatitis C was unhelpful. It criticised the state for lacking relevant strategies to tackle HIV.

The Victorian State Government was unavailable for comment, but a Human Services departmental spokesman said hepatitis C had supplanted HIV as the major health concern.

- Taken with thanks from *The Age,* website, 17/2/99.

10 year follow up

As reported in *Hepatology* 1998;28:1121-1127, research has been done into the long-term outcome of chronic hep C patients who had an initial sustained response to treatment with interferon. Evaluation of ten patients, treated between 1984 and 1987, was conducted.

Of five patients who had a six month sustained response, all still had undetectable viral loads. The other five, who had not responded after treatment, still had chronic hepatitis, some with acute complications.

The research was able to point to a favourable long-term outcome for those who had enjoyed a sustained response after treatment.

- By Douglas Barry

Healthcare worker project

The Hepatitis C Council of NSW has been appointed to run a project developing hepatitis C education for healthcare workers (HCWs).

Funded jointly under the Commonwealth/State Public Health Outcomes Funding Agreement, the six month project involves the appointment of a project officer based in the Council's office.

Based firmly on the principle of community and HCW involvement, the project will result in the development of HCW education strategies in NSW, as well as run inovative pilot programs in metropolitan and rural areas.

Alarming HCV rate in US veterans

The US Department of Veterans Affairs has instigated a concerted surveillance system for detecting both viral and antibiotic-resistant infections among retired US armed service personnel.

Termed the 'Emerging Pathogens Initiative', the scheme is facilitated through more than 170 Veterans Affairs medical centres and over 600 associated clinics.

During the 1998 financial year, 95,447 HCV blood tests were carried out. Of these, 29,799 returned a positive result. On the surface this would suggest an HCV prevalence rate of approximately 31% among US service personnel. It must be remembered though, that testing may have been targetted at those at greater risk.

Vietnam veterans accounted for 63.7% of positive test results; 18.5% were from the post-Vietnam era; 4.5% from the Korean era; 4.2% from the post-Korean era; 9.1% from all other periods of service.

US Department of Veterans Affairs spokesman, Gary Roselle, said they clearly had a population that was very vulnerable to hepatitis C.

"These findings give us the ability to target our [healthcare services] and project our future needs", he said.

The VA is beginning to face the problem head on. This year, it plans to issue a set of treatment guidelines for the disease and establish two HCV research and education "Centres of Excellence" in Miami and San Francisco.

While they are steps in the right direction, the proposed guidelines do not go far enough, according to Jere Hough, a VA patient and HCV activist. Hough says the problem is that the VA "is limited by what the FDA (US Food & Drug Administration) has approved and what the FDA will allow."

"If doctors used lab tests to modify doses, people would be much better off. You could make treatments far safer and more effective," Hough says. He believes using different interferons, different doses, and especially higher doses at the beginning of therapy could improve the number of people who respond to treatment.

Many people relapse or fail to respond to treatment. But Hough feels *relapse* or *failure* may be inappropriate terms. "It just means clinicians didn't use adequate dosages or treatment regimens to begin with."

In essence, the message is not that people failed treatment, but that treatment failed them. Nonetheless, Hough says the fact that the VA intends to issue guidelines is "an important step in the right direction" and shows they recognise and are making an effort to address the HCV problem among retired armed services personnel.

- For more information on this story, visit the website: http://www.wellweb.com/Hepatitis/whats_new_in_hepatitis_research.htm

  [Here in Australia we are aware that our Armed Services routinely discharge personnel who are HCV positive (see Ed24, P7; Ed22, P31), a policy we feel is unwarranted. At time of publication, we are unaware if the Australian Armed Service has any policy on treatment, care and support for current or ex defence force personnel. We shall report back within Edition 26 - Ed.]

In retrospect

Hi I' m Marty.

I wrote a couple of articles last year for *The Hep C Review*, as I was on the interferon treatment program and thought others might benefit from my experience (Ed21, P12; Ed22, P10). Thanks to those who emailed me, and apologies to a couple whose details were accidentally erased before I could respond.

It was a long, hard year, and I am sad to say that after I went off the medication the virus returned. Actually now I can't believe I even considered doing it, given the highest percentage of 19% for sustained cure. I'm not really a gambler, but am a positive thinker, and when offered the expensive medication a trial study for free, reckoned I would give it a go.

If you read my articles you know that I tried many other natural therapies along with the medication to help support the body, and hopefully sustain the cure. Indeed I feel they did help me tolerate the side effects, but still it was the hardest thing I've ever done.

Over the year other than the usual side effects of fatigue, headaches, irritability, hair loss, etc, these health problems occurred: loss of my thyroid, reflux, esophogitis, abnormal cells in the cervix, deterioration of my eye sight and lung capacity. The doctors say these things may or may not have been caused by the interferon.

Most of these things are mentioned on the product information sheet under adverse reactions, "as rarely reported". The print is not legible with normal eyesight and I had to blow it up 100% to read it. Be sure you read it. Beware the list is ever so long.

Personally I don't think we are properly prepared, aren't told all the things that could go wrong, and the drug company should be more specific and list percentages of people who suffered these reactions. This would give us a better idea if we want to chance the treatment.

I was a little confused and shaken when two different doctors referred to this treatment as a type of chemotherapy. If described this way to me in the beginning I think the red warning flag would have gone up in my head.

I was also shocked towards the end of the treatment, when a visiting American friend, up on current medical treatments and with friends with Hep C, asked me, "why are you doing this treatment? In the States it is considered ineffective and obsolete. The standard treatment is now combination therapy with a sustained response of 40 to 60% depending on your type and other details."

I tried to explain to her that here we aren't offered the combo unless we have first tried and not sustained cure with monotherapy (interferon alone). All she could do was shake her head.

Of course the combo is much harder to tolerate, but given the better chances of cure and 6 months instead of 48 weeks of treatment I wish I had waited for things to change here. Given time they will, and hopefully even a better drug will come along which is more people friendly.

I would like to say that the clinical nurses at RBH were fantastic, very caring, encouraging, understanding and friendly, the doctors too, though over-burdened, were helpful and genuinely concerned.

In retrospect, of course given the health problems that I incurred, and the fact that I didn't sustain the cure, wish now that I had just accepted and learned to live with and love my virus, taking extra special care of my liver, as it seems that resistance (fighting it) caused persistence.

Love and peace to all of you, Marty

(thanks Marty for your photo)

Washington DC hep C conference

By Kathy Gresham Dreyer.

I spent today at the Hepatitis Foundation International (HFI) Conference on Hepatitis C in Washington DC. I am going to be posting a few things as I have time to, because they are just so darned exciting I don't want to wait until I get home. So please forgive typos and fuzzy thinking. Please also bear in mind that I am not a scientist and these are just the notes I've been taking.

Fibrosis

One of the most exciting discussions for me was called *Fibrosis and Indicators of Progression of HCV.* The lecturer was Scott Friedman, MD, Director of Liver Research, Mount Sinai Medical Center, New York

Dr Friedman started out by saying that in the area of fibrosis there has been lots of progress. The new thing will be anti-fibrotic therapies because they have FIGURED OUT HOW FIBROSIS WORKS!

He said it is pretty straightforward and used various slides to explain his work. (If HFI doesn't publish them I am going to post them on our webpage).

Here is the deal: hepatic fibrosis is the liver's wound healing response. It is a well intentioned response that gets out of hand. The more scar tissue that forms, the more the functions of the liver are blocked. He thinks the point of therapy should be to slow down the accumulation of scarring.

He said there is no fibrosis in acute hepatitis but with chronic hepatitis, you do get fibrosis (which is REVERSIBLE) which often progresses to cirrhosis (which is irreversible).

Dr. Friedman went on to explain fibrosis progression. Now I don't know how this relates to the stages that we generally talk about, but when it comes to fibrosis, the new way it is measured is F-0 to F-4. F-0 is normal liver; F-4 is cirrhosis.

F-1 is central vein and portal tract fibrosis,
F-2 is a few septa (bridging and scar tissue)
F-3 is numerous septa
F-4 is cirrhosis (nodules have formed)

The interesting thing they have found is that for each person, the interval of time between stages is the same. For example, if you are a rapid progressor, the time between stages is short. If you are a slow progressor, the time it takes to move from one stage to another is longer.

In simplified terms: if it takes you twenty years to move from F1 to F2, then it will take you twenty years to progress to F3. By the same token, if it takes you 5 years to progress from F1 to F2, then it will take you 5 years to get to F3 and 5 more years to get to F4. It is a linear progression.

Some guy in France named Poynard did a study comparing more than 1100 patients. (My notes are fuzzy here) People who took treatment benefited from anti-scarring activity even though they didn't clear the virus... something like 85% or maybe more. My notes aren't clear here because I was so excited.

He thinks a realistic goal is, that if you can't clear the virus, to spend your life at Stage 2 – an asymptomatic Stage 2.

Cirrhosis factors

The factors associated with progression to cirrhosis are:

* You are older than 40 when you get infected
* Your daily alcohol intake is more than 50 grams (10 standard drinks)
* You are a male (they think that natural estrogens can be protective)

Now the good news. Dr. Friedman is very optimistic about anti-fibrotic therapy. He thinks it will be available within 5 to 10 years

The question that must be answered is what is there about the host (that's you and me) that makes some people rapid fibrosers and others slow fibrosers. The answer: subtle differences in the immune system we were born with.

Questions that researchers felt had to be answered about fibrosis so they could understand it well enough to be able to develop therapies were:

1. What is the cellular source(s) of extracellular matrix in liver injury and fibrosis (fancy words for scarring)?
2. What provokes that matrix accumulation (scar tissue build up)?
3. What are the potential therapies to defeat that matrix accumulation?

We were then shown slides of a cross section of the liver cells. The liver is composed of sinusoids - kind of like the capillaries of the liver. It is made up of layers - endophelial cells, kupfer (macrophage) cells, hepatocyte cells - that perform most of the liver functions. The stellate cell wraps around the sinusoid. It is the storage depot for Vitamin A and it floats (I don't remember why I thought that was important).

Researchers came to the conclusion that the cell that is activated in fibrosis is the stellate cell. As a side note, Dr. Friedman told us that this cell is a repository for Vitamin A and that Vitamin A is endogenously fluorescent - that is, it naturally glows in the dark. It is a coincidence that when it was named for its shape back in the 1800s, and now when examined under certain lights, it shines like a star (stella is the Latin word for star).

Their research has CONCLUSIVELY established that the damage to the liver is coming from these stellate cells. The damage occurs in the area between the hepatocyte cells and the endothelial cells.

Vitamin warning

Before I go any further: DO NOT TAKE ANY EXTRA VITAMIN A !

Dr. Friedman said vitamin A supplementation is contraindicated (not recommended) and also megadoses of anything at all are contraindicated. Because excess vitamin A can trigger this fibrosis.

Okay, the stellate cell begins to activate and somehow loses the Vitamin A or some other substance (sorry for the bad notes but it's been a long time since college). All the liver cells in cirrhosis are unhappy because they cannot function normally.

The stellate cells contract when they are activated by damage. They act like smooth muscle cells. There is a class of drug that is already being used to "uncontract" smooth muscle cells ... cytokine endothelans. He thinks, no he knows, the drug companies are jumping all over this like stink on you know what (my words, not his) to come up with good anti-fibrotic therapies for the liver.

He thinks the best treatment would be viral clearance ... but that doesn't work for everyone (like me). It's hoped that anti-fibrotic treatment will keep everybody in early stages. I think if you stop damage that you can reverse the damage because the liver will regenerate.

Interleukin-10

He opened the floor up for questions and that is when the most interesting thing occurred. A man from Florida said that he was in an Interleukin-10 study at Shands Hospital in Florida and that ALL 80 patients in the study had reversal of their fibrosis. Dr. Friedman said that was very encouraging because Interleukin is a cytokine that is known to be anti-fibrotic.

So, that's the report from Washington so far.

- Kathy Gresham Dreyer is a member of the Los Brazoz Charitable Foundation, Houston Texas. <kdreyer@texas.net>

[Several research groups in Australia are doing outstanding work on liver fibrosis. Prof Friedman has visited here and there is collaboration between Australian researchers and his group. This kind of research is very valuable and is one of many research areas we feel requires additional funding - Ed]

Predicting response - cutting out the guesswork

By Douglas Barry

Treatment with interferon can last for up to 6 months, 12 months or even longer. Sometimes a patient can suffer with side effects and they can be severe, disrupting work or generally affecting quality of life.

So it's necessary for doctors to be able to establish as early as possible whether the treatment is not working - a non-response. If a non-response can be predicted early in treatment, then the patient is saved both unnecessary cost and any discomfort from side effects.

A number of means exist for assessing whether the therapy has been effective after it is completed - a sustained response. They include a PCR test which indicates the loss of measurable virus in the blood - HCV viral detection test; another way is to examine the state of the liver enzymes - the ALT test.

As reported in *Hepatology* Sept 1998; 29 (3): 362-368, a group of researchers in America used both the HCV viral detection test and ALT methods to test 66 patients on interferon over 6 months of treatment. They were assessed at regular intervals throughout that period, and then 6 months later.

It was found that the HCV viral detection test was a more accurate predictor for both non-response and sustained response. The researchers concluded that, using this test after three months, they could have predicted a non-response for 75% of the patients.

A similar result reported in the *Journal of Viral Hepatitis* Nov 1998; 5 (6): 399-406, was obtained last year by a research group in Germany.

The aim of their study was to find factors which would enable them to predict, before treatment, those of their patients with chronic hepatitis C and treated with interferon, who would enjoy a sustained response and those who would not respond at all.

Of the 87 patients studied, 21% had a long-term sustained response.

The researchers found that there was nothing about the patients which could provide an accurate predictor of responses. There were certainly a number of pre-treatment viral factors, such as the viral load of the patient, which could give some indication of response. They also concluded that, using the HCV viral detection test, a non-response could be predicted after three months of treatment.

- Douglas Barry is a volunteer writer/reviewer with *The Hep C Review.*

[The above evidence suggests that monitoring treatment by measuring ALT levels is a second rate option. This would imply that if treatment monitoring is to improve, the government must free up access to PCR testing and other evolving technologies. Some Australian clinicians are quoting studies that report good evidence for treating early, as opposed to currently waiting till ALTs are elevated - Ed]

Combination therapy trials - two therapies may be better than one

by Douglas Barry

Recent trials (reported below) have suggested that the use of a combination of interferon with ribavirin may be more effective than interferon alone in the treatment of chronic hepatitis C .

Available now for some years, interferon has the ability to inhibit viral growth. In up to 40 per cent of patients with chronic hepatitis C, a sustained loss of detectable HCV has been achieved after twelve months of standard treatment.

Study One

As Initial Treatment:

This random trial was conducted by the Hepatitis Interventional Therapy Group in the United States. The Group randomly assigned 912 patients with chronic hepatitis C, who had not been treated previously, to receive a combination of interferon and ribavirin or interferon alone. Treatment was given for 24 or 48 weeks.

Then, 24 weeks after the treatment was completed, the patients were assessed. Of those on the combination for 24 weeks, an undetectable viral load was found in 31%; for 48 weeks, 38%. For those on monotherapy, the figures were 6% and 13% respectively.

Study Two

As Initial Treatment:

Again, this trial, undertaken by the International Hepatitis Interventional Therapy Group in Paris, was for chronic HCV patients receiving treatment for the first time.

832 patients were randomly allocated one of three courses of treatment:

- interferon with ribavirin for 48 weeks
- interferon with ribavirin for 24 weeks
- interferon alone for 48 weeks.

But this response has been found to be temporary. After treatment has ceased, no more than fifteen per cent of patients maintain this response. Higher doses of interferon and up to two years of treatment produce improved responses. However, such measures are costly and are often poorly tolerated by people.

Ribavirin is an antiviral drug, effective against a range of DNA and RNA viruses. How it works remains unclear. Used alone, generally, it does not effect a reduction in HCV RNA levels. Ribavirin can cause a form of anaemia, bringing breathing difficulties, fatigue or poor resistance to infections. Additionally, it has been shown to cause birth abnormalities and for this reason, contraceptive precautions must be taken while on the treatment.

That ribavirin, however, may enhance the effect of interferon, leading to a more vigorous immune response against HCV, has been suggested by three recent trials in America and France (see below).

Again, 24 weeks after the completion of treatment, a sustained loss of detectable HCV was found in 43% and 35% of those taking the combination therapy for 48 and 24 weeks respectively.

A similar result was obtained in 19% only of those on interferon alone.

Study Three

As Treatment after Relapse:

345 patients who had previously received interferon and had relapsed after an initial response were tested by basically the same American Group.

For 24 weeks, 173 patients with chronic HCV, were randomly assigned the combination therapy. Monotherapy was similarly administered to 172 patients. Of those taking the combination therapy, 49% had a sustained response when assessed 24 weeks after treatment was completed, compared to 5% of the others on monotherapy.

Summary

It is clear that these trials of combination therapy suggest an important advance in treatment research for chronic hepatitis C. When used both for the initial treatment and after relapse, interferon and ribavirin have achieved substantially higher sustained responses, than with interferon alone.

Serious questions, however, remain to be answered:

A treating doctor has to use certain criteria when deciding on the commencement and the duration of combination treatment. These trials do not shed any light on what those criteria should be.

Once more, side effects are an important issue. Given in combination for more than 24 weeks, these medications were observed to have clinically significant side effects. In *Test One,* 21% on the combination for 48 weeks, had to discontinue treatment. In *Test Two,* 19% of the patients, similarly trialed, dropped out because of adverse side effects. (For a further discussion of side effects, see p14.)

Doubt must also arise as to whether patients, outside of a carefully monitored trial, would comply with the treatment regimes for six or twelve months. They may be less motivated and so more ready to discontinue the treatment when severe side effects are experienced.

Despite these doubts, there is room for some cautious optimism. Many other antiviral compounds may soon be available for the treatment of hepatitis C . The knowledge of the scientists about such things as molecular engineering and the very nature of HCV infection increases daily. The researchers are rising to the challenge, however daunting, of developing the most effective and least costly therapies for HCV infection.

- Douglas Barry is a volunteer writer/reviewer with *The Hep C Review.*

"Study 1" *The New England Journal of Medicine,* November 19, 1998 -- Volume 339, Number 21: 1485-92.

"Study 2" *The Lancet* 1998 Oct 31;352(9138): 1426-32.

"Study 3" *The New England Journal of Medicine,* November 19, 1998, Volume 339, Number 21: 1493-9.

Forewarned

Just a note about the ribavirin/interferon treatment. I have just completed a six month treatment. I just want everyone to know that the treatment isn't a nice treatment.

The massive mood swings, the sore hands and feet, always light headed, loss of memory, fevers, head aches, my eye sight went on me, and hair loss. This treatment cost me a lot. My family and partner have seen the lot.

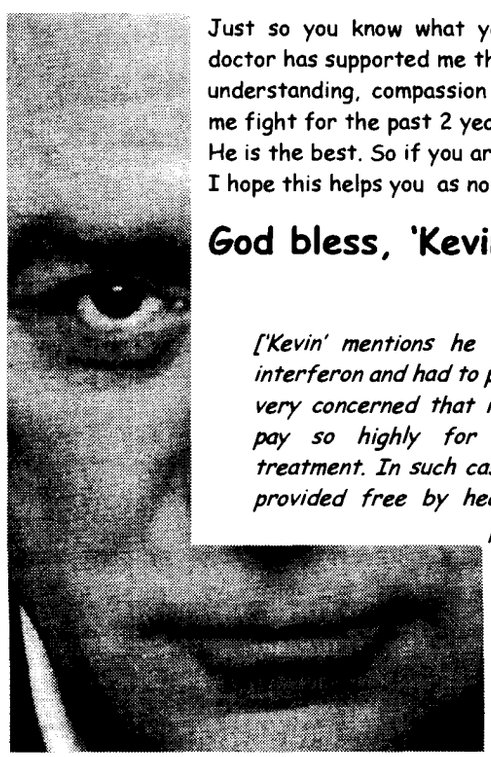
I got the result I wanted from the treatment - 2 negative PCRs and normal liver function. So I am happy. I am not telling you this to complain, but so you will know what you are in for, because no-one told me. My specialist at the treatment centre was good. But [his two nurse offsiders] were not very supporting. I was put on the treatment and left by the nurses, very unsupported to deal with it on my own. The depression from the treatment was massive. So if you do suffer from depression think twice about going on the treatment.

I didn't qualify for free S100 interferon and had to pay for it myself. The massive over pricing of the drug cost me heaps. For the first month, just for two weeks cost me $970. My local chemist added his little bit on top. Everyone was getting it from you. They all want money from you. [My Professor got] me the Ribavirin on compassionate use.

So I wasn't just a little sick. I had to have this treatment this year. I have had the virus for 18 years. My treatment centre helped me out twice with interferon.

This virus has robbed me of ever working again and I am a pensioner. [They] get you to sign away all your rights so you can get the treatment then they charge you through the roof for it. This treatment cost me $5400.

Don't get me wrong, I am happy about the outcome. It will give me a better life for now. But maybe the bastard virus isn't really gone and fights back, and does it all again to me again and robs me of the lot.



Just so you know what you're in for. My private doctor has supported me through it all with respect, understanding, compassion and kindness. He's seen me fight for the past 2 years to win and I will fight. He is the best. So if you are going on this treatment I hope this helps you as no-one told me.

God bless, 'Kevin'

['Kevin' mentions he was ineligible for S100 interferon and had to pay for it himself. We are very concerned that individuals might have to pay so highly for access to combination treatment. In such cases, interferon should be provided free by health authorities so that people accessing compassionate use ribavirin can proceed with combo treatment without having to 'mortgage the house' - Ed].

(model/s used above)

Side effects from treatments

by Douglas Barry

It doesn't seem fair

First there was interferon for the treatment of chronic hepatitis C. Now there are trials being conducted on people with HCV, using a combination of interferon and ribavirin - with promising results. (See article on *Combination Therapy Trials*, P12)

You'd think there'd be real cause for hope in these advances in treatments. Perhaps at last, there's real progress being made in those laboratories and research centres.

In some ways, there is cause for excitement. But the problem of the side effects associated with those treatments dampens that excitement. It just doesn't seem fair.

If you are thinking about starting a course of treatment for hep C, then it's best not to forget the possibility of there being side effects. Talk with your doctor about them, about their severity, how they'll affect your life, and how long you might expect them to last.

One thing is certain - there's no shortage of trials into treating HCV, and there are plenty of reports from all over the world about the side effects observed.

Here we summarise some of those reports:

Dermatological side effects

As reported in the *European Journal of Gastroenterology & Hepatology* 10: (11) 933-939 NOV 1998, a group of 45 patients with chronic HCV were administered interferon therapy for between 12 and 18 months. There was also a control group of people with chronic liver disease who did not receive interferon treatment.

Within six months, two of the 45 developed *lichen planus*, an itchy skin condition normally found on the inside of the wrists. A third patient developed *apthous stomatitis*, painful ulcers inside the mouth. Therapy was discontinued for this person. When therapy was completed, the symptoms of *lichen planus* went away.

None of the control group displayed any dermatological problems.

The researchers concluded that interferon may rarely induce skin conditions which, in the case of the *lichen planus*, were both mild and temporary.

Thyroid dysfunction

As reported in the Journal of *Interferon Cytokine Research* 1997 Jul; 17 (7): 409-11, a small trial conducted in Ireland attempted to assess the frequency and nature of thyroid abnormality associated with the use of interferon alone and with a combination of interferon and ribavirin.

About one-quarter of the 19 patients studied showed some thyroid dysfunction, there being slightly fewer in the group on the combination therapy. It was felt that the HCV genotype may influence the development of these abnormalities.

While acknowledging the limitations of such a small trial, the researchers concluded that patients on interferon therapy need regular thyroid function testing.

Neurovisual complications

A number of doctors in Athens treating patients with chronic hepatitis C had noticed in 1994, that, with three of them receiving interferon therapy, they began to suffer with blurred vision. Two of them also displayed signs of depression.

On completion of the interferon treatment, the symptoms were no longer apparent.

The doctors concluded, on the basis of their observations of these three patients, that interferon treatment may be complicated by damage to the nerves connected to the eyes.

Over the next four years, the same doctors in Athens conducted more exhaustive ophthalmologic testing on over 50 patients with chronic hepatitis B and C who were being treated with interferon.

They concluded that mild neurovisual impairment was a frequent complication associated with interferon therapy. Older patients and those with hepatitis B appeared to be more susceptible. They also suggested that the visual impairment may be long-lasting.

(For the above two studies, see *Hepatology* Sept 1994; 21: (3) 474-7 and *Hepatology* May 1998; 27: (5) 1421-1427.)

Summary

The results of these observations, together with the already-known side effects, such as depression, lethargy and flu-like symptoms, should not deter anyone considering treatment with interferon, either alone or in combination. Complications are experienced by only a proportion of those on therapies and to varying degrees.

However, it is always better to be forewarned, and, armed with this information, fruitful discussions can be had with your treating doctor.

- Douglas Barry is a volunteer writer/reviewer with *The Hep C Review.*

Kim's hep C story

Jeez, where do I start?

I'll start the day I received the first phone call. My ex, whom I am not friends with, called me out of the blue. He told me that he had tested positive for hep C and that I should be tested.

We had studied the art of better living through chemistry back in the late 70's, early 80's.

Anyway, my first antibody test was positive. I was a little worried but not too much. I had already had Hep A and been vaccinated for B so how bad could it be. My doctor, a friend, called his associates to learn more. He ordered a PCR viral load test.

About a week later I got the most devastating phone call. He called about 10.00 pm, obviously saddened and told me that my virus count was 513,000/ml. He admitted that he was in the dark about hep C and recommended me to a gastro doctor. His last words to me were "you're in my prayers". I had worked for this man for two years, this was not his normal demeanour.

When I entered the new doc's office I was greeted by a smiling, cheerful, young man. James, my new nurse was to become one of my best supporters throughout this journey. My new doc is a woman, very kind and seems to be quite knowledgable. She is open to the info that I bring her from the net. I like her very much.

The philosophy of my health care professionals is to treat their patients, as well as the disease.

The dreaded liver biopsy. The needle stick to deaden the site was painful but bearable. The actual biopsy was a breeze but the neck and shoulder pain that followed was horrible. Luckily, my doctor is a believer in pain management. A couple of Darvocet later and I was going home in the morning. The results were mild hep C - no liver damage!

My interferon experiences

OK, I haven't touched a needle in over 11 years. I don't know if I can do this! Well I can do it with a little help from a Valium to keep me calm. I did suffer through several panic attacks at first, hence the Valium. Needles scare me to death!

Now the painful part. My initial experience with IFN (interferon) was horrible. My entire body hurt so badly! I prayed for God to render me unconscious it hurt so bad. My doc put me on Darvocet to control the pain. After 2 weeks I was able to return to Tylenol and pitch the Darvocet. My next battle was fatigue and depression.

I had just graduated from college and I was too weak to look for work. All that hard work and now I was too sick to get a job. Remember, I wasn't sick before the IFN. I had no idea I was carrying this virus.

I felt like I was at the end of my rope. I have no insurance so money was getting tight. All these new expenses and no extra income. This is where I tell you about my wonderful family.

I am married to the dearest man I have ever known. We have two daughters, 12 and 14 years. My husband has been the most affected by my illness. He works so hard to pay the bills, lots of overtime, but we still come up short. His stress level went past an acceptable level months ago and his own health is starting to suffer.

By the way none of my family members are HCV positive, we checked. My oldest daughter was terribly frightened, lots of tears. We had a couple of talks about IDU, the uncertainty of the future, and that I wasn't going anywhere yet! She is adjusted now. Except for finances things are pretty normal around here.

Back to the IFN story. I am an excellent responder to the therapy. After 4 weeks my PCR dropped below 100/ml and after 3 months I was non-detectable. My side effects aren't too bad any more. Still some fatigue and headaches, but I can work. I am on IFN until June.

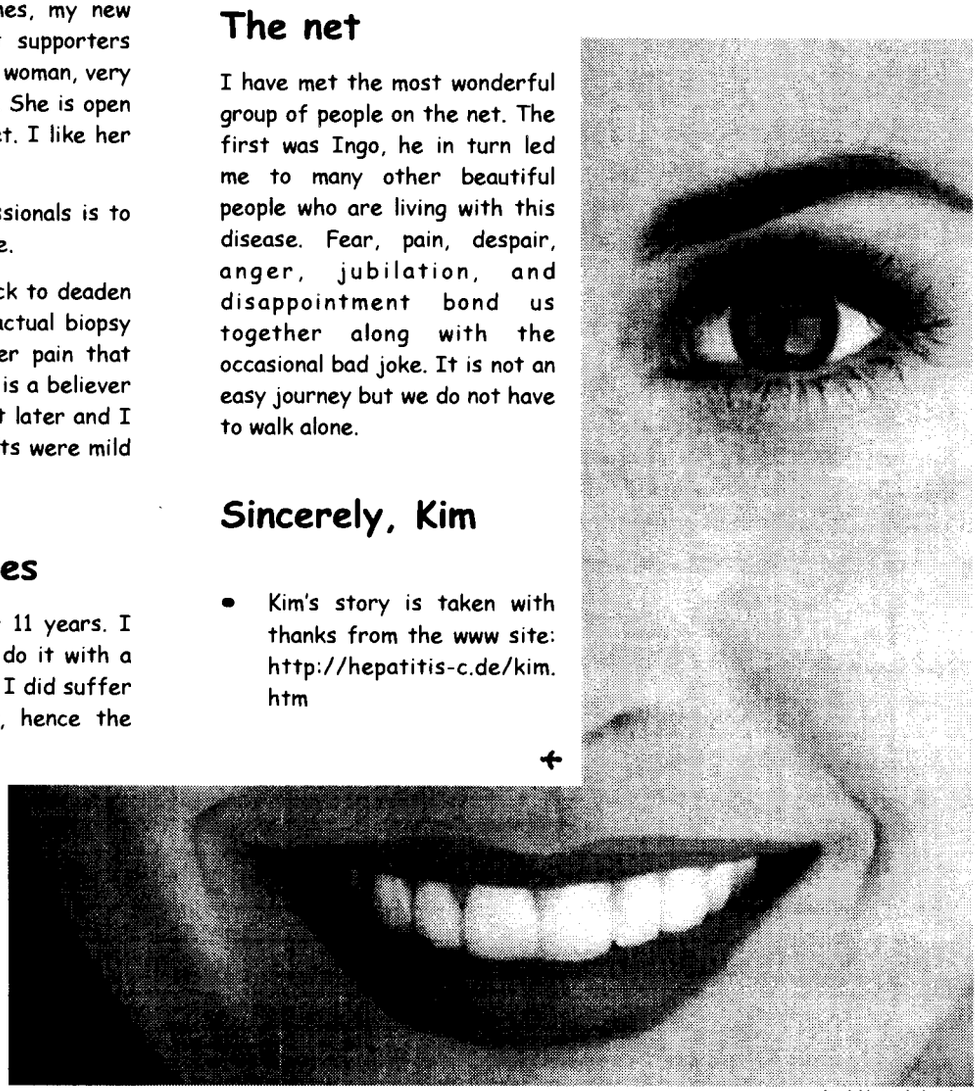
The future looks promising. I know that the virus may resurface and probably will but it won't keep me from following my dreams today.

The net

I have met the most wonderful group of people on the net. The first was Ingo, he in turn led me to many other beautiful people who are living with this disease. Fear, pain, despair, anger, jubilation, and disappointment bond us together along with the occasional bad joke. It is not an easy journey but we do not have to walk alone.

Sincerely, Kim

- Kim's story is taken with thanks from the www site: http://hepatitis-c.de/kim.htm



(model/s used above)

Rimantadine ruled out?

A pilot study of rimantadine for people with chronic hepatitis C who'd previously tried interferon therapy but hadn't responded, was recently reported in the *American Journal of Gastroenterology* 1999 Apr; 94 (4): 990-3.

Reprinted here is an abridgement of the research abstract (overview).

Objective

Therapy options are limited for chronic hepatitis C patients who have not responded to a course of interferon therapy. Recently, a 6-month course of amantadine was shown to result in a sustained virological response in chronic hepatitis C patients who were unresponsive to interferon therapy.

The aim of this current study was to evaluate the effect of rimantadine on chronic hepatitis C patients who had not responded to interferon therapy.

Methods

This was an open label trial involving 17 people who were treated with rimantadine 100 mg b.i.d. for 6 months. Changes in serum aminotransferase activities and HCV-RNA levels were determined.

Results

Mean alanine aminotransferase activities and HCV RNA levels did not change significantly during therapy. HCV RNA remained detectable in all patients throughout therapy. Neurologic symptoms (headaches, nervousness, and dizziness) developed in 5 people. Two people required dose reduction after 12 wk of therapy because of dizziness.

Conclusion

Rimantadine has no significant antiviral activity against HCV.

Author

Fong TL, Fried MW, Clarke-Platt J, Center for Liver Diseases and Transplantation, Cedars Sinai Medical Center, UCLA School of Medicine, Los Angeles, California 90048, USA.

- Taken from the internet email list: HEPV-L

HCV at sea

Back in my teenage years and up until recently, I spent a lot of time off my face. One thing lead to another and now I have hepatitis C. It was probably fifteen years ago when I caught it but I only found out that I had it in 1994.

I look back now and try to remember why I sought refuge in the chemical world. I can think of some answers to this question but I won't bore you with these except that it had to do with the way I viewed myself and how I got on with other people.

What is more important to me these days is how I cope with problems and frustration now.

Sure I still come up against difficulties - who doesn't, especially having hepatitis C.

What I have found is that by filling my day to day life with positive things, I get real enjoyment out of life - and all those frustrations and problems seem that little bit easier to deal with.

What are those positive 'things'?

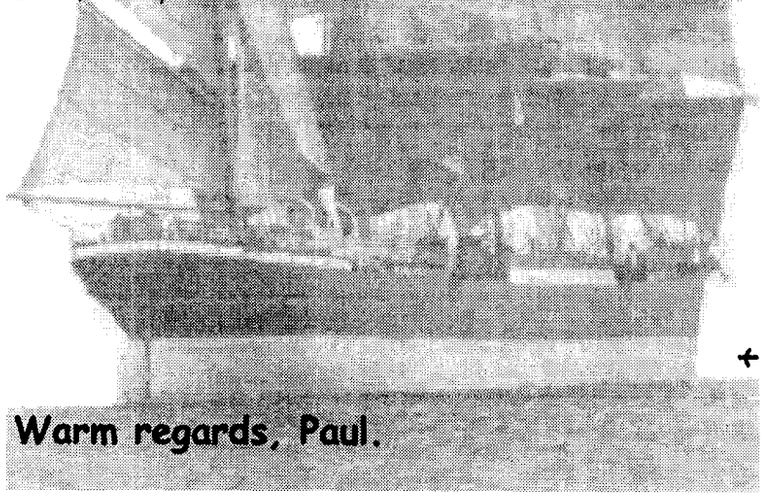
Number one is my nine year old daughter. Like the song says, she's a "little ray of sunshine". There's no doubt about it.

I've grown closer and closer to my own parents and this has been wonderful too. Maybe its because they are getting older and I can't take it for granted that they are always going to be around. Whatever the reason, I'm spending more and more time visiting them - and also my brothers and their kids.

Amongst other positive 'things' is the time I spend doing volunteer work on the old *James Craig*. She is an awe inspiring ship and the more time I am working on her, the more she impresses me.

Going back to what I've previously mentioned - my work on the 'Craig' brings me into contact with lots of other people. The restoration and maintenance work we do relies on teamwork, as will the actual sailing when she's ready. And when is that? It is estimated that in early 2000, she will be sailing out the Sydney Heads possibly heading for NZ or some other distant port!

If your hep C is getting you down and you want to get out of the house and meet other people, come on down to Blackwattle Bay, Glebe, and say hello. Just ask for Paul.



Warm regards, Paul.

Kids & interferon therapy

By Sue Conrad

In Australia, it is believed that relatively few children have been infected with hepatitis C since 1990 (when the blood supply was routinely screened). Mother to child transmission during birth is between 1% and 5%, and there are a number of factors such as viral load, other infections and birth complications that determine the likelihood of this occurring. Anyhow, as I hadn't personally read any research relating to children and interferon therapy, I went in search of some.

I gathered nine research articles about children and hepatitis C, seven of which focused on treatment. I must say, there isn't a great deal of research being done involving children but this is understandable as being involved in long term treatment trials involves a great deal of commitment and can be difficult for both children and families.

The articles I found were about studies conducted mostly in countries where people infected with HCV have genotypes other than those most seen here in Australia.

While this makes it impossible to generalise about treatment of children with hepatitis C, it is interesting that in all the studies I read, children had less severe liver disease than adults did.

The genotype problem aside, another problem with interpreting research is that in almost all the studies, only small numbers of children were involved. When only small numbers of people undertake treatment at a centre, it is difficult to make assumptions about how the treatment will affect others at different places with different circumstances. Given these limitations, the summary that follows is just a glimpse of what researchers are writing about. It is not information that has been established as fact.

Interferon is not an approved treatment for children in Australia, and children are not eligible for subsidised treatment under the S100 protocol. This is primarily due to the lack of controlled trials for children, and concerns over the effects on growth caused by interferon.

This effect of interferon on children appears to be significant, especially in young children who are growing rapidly. Children who undergo interferon treatment seem to experience similar side effects to those that adults experience. Commonly these are flu-like symptoms, fever, fatigue, irritability, nausea and weight loss.

In most cases across the studies I read, the flu-like symptoms disappeared after 2-4 weeks of therapy. Most studies found that interferon was fairly well tolerated by children. A few of the studies I found monitored nutritional status plus height and weight in the young folk. The weight loss during interferon therapy was most problematic when therapy spanned 6-12 months.

It's thought that this is an effect of interferon itself, and not related to symptoms of nausea, vomiting, and other stomach disturbances. It appears that weight returns to the normal range by 6 months after the completion of therapy. More research is obviously needed to determine the extent to which weight loss and the possible slowing of growth can affect child development.

Viral clearance in children following interferon therapy probably occurs at about the same rate as it does for adults. Clearance of the hepatitis C virus following interferon therapy occurred among between 0% - 41% of children across the studies I read.

These results are very hard to interpret. Because of the differences and problems in the ways each study was conducted and/or reported, not much can be concluded about how successful interferon treatment is for children.

When other more effective treatments become available, children with hepatitis C may be included in trials that are controlled and well documented.

There are only 2 consistent findings in the studies I read (and remember - this may mean nothing). These are firstly, that children are slow to develop liver damage as a result of HCV infection (as are adults); and secondly, that they tolerate interferon treatment quite well.

So what does this all mean? Not much more than many of us already assumed I guess. Rest assured though, when some new exciting research happens, the Hepatitis C Council will let you know about it.

- This article is reprinted with thanks from *Hep C News* - newsletter of the Hepatitis C Council of QLD (Issue 9, Vol 4).

(model/s used above)

Hepatitis C: a review of Australia's response

Reprinted with thanks from the original report.

The challenges hepatitis C presents - as outlined in this review - pose particular difficulties for governments, public health officials, community-based organisations and health professionals. The difficulties stem from the large number of people already infected; the high annual incidence rate; the difficulty associated with interventions where the main risk factor is connected with an activity that is both illicit and highly stigmatised; a shortage of research findings to guide the design of a response; and the limited range of treatments currently available.

If Australia is to respond effectively to the epidemic, each of the challenges must be confronted and overcome.

Challenge 1 - Reducing the number of new hepatitis C infections

1. Provision of sterile needles and syringes, sufficient to meet demand, so as to reduce the prevalence of unsafe injecting.
2. Education programs aimed at reducing illicit drug use, particularly injecting drug use.
3. Provision of drug treatment programs such as methadone maintenance, sufficient to meet demand, so as to reduce the prevalence of unsafe injecting and the prevalence of illicit drug use.
4. Provision of safe injecting places to reduce the prevalence of unsafe injecting.
5. Education programs targeting injecting drug users through specialist agencies (such as peer-based programs developed and undertaken by user groups) and the use of mainstream health care workers, so as to reduce the prevalence of unsafe injecting and the prevalence of injecting.
6. Education programs and the provision of preventive measures in prisons.
7. Measures to reduce the number of injecting drug users in correctional centres through the adoption of cautioning systems for first offences and diversionary sentencing.
8. Removal of legal impediments to achieving a higher proportion of safer injecting amongst injecting drug users.
9. Establishment of an agreed core service structure and realistic output targets for education and prevention services.

Challenge 2 - Improving treatment and care for people with hepatitis C

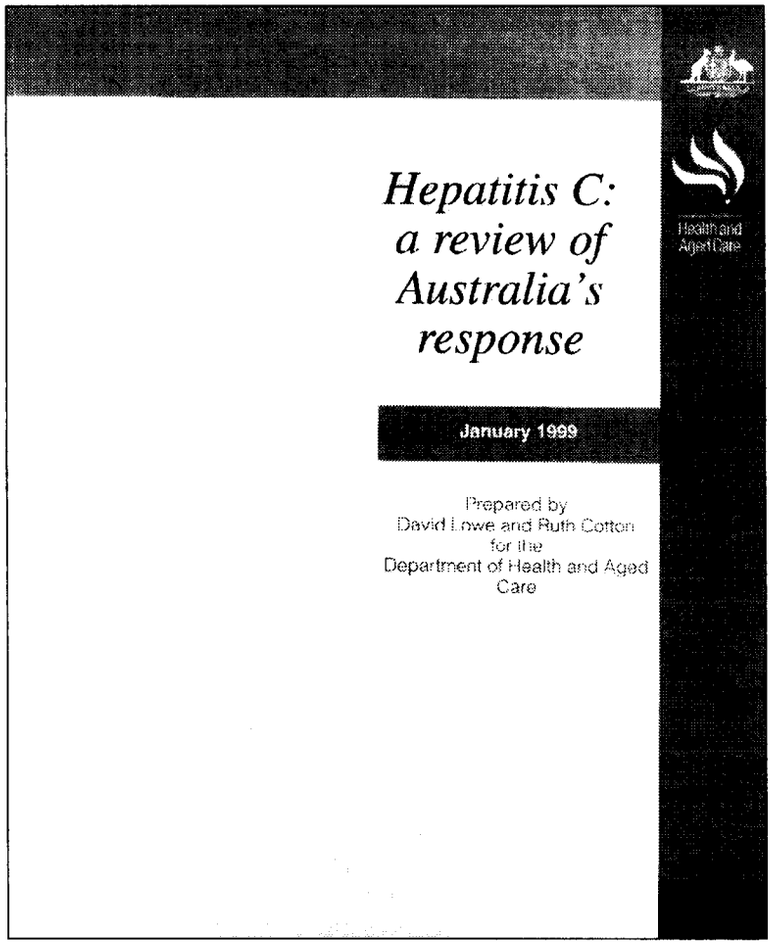
1. Development of an agreed policy on hepatitis C testing.
2. Development and implementation of primary health care models, by general practitioners and public sector community clinics to deal with the health care needs of population groups with hepatitis C to ensure optimal access to counselling, testing and management.
3. Enhancement of the capacity of liver clinics in hospital settings, sufficient to meet demand.
4. Access to the full range of treatment and care services for people who are incarcerated.
5. Established mechanisms for the continuing education of general practitioners and others who work in hepatitis C treatment and care and the incorporation of advances in care in clinical practice.
6. Provision of information and support, including health maintenance and monitoring for people with hepatitis C, through community organisations such as hepatitis C councils and user groups.

Challenge 3 - "Getting the research right"

1. Adherence to a set of guiding principles.
2. Transparent processes for determining research priorities and for funding the 'best buys' for Australian hepatitis C research.
3. A research plan that sets out priorities, mechanisms for funding, and the role of national research centres funded under the National HIV/AIDS Strategy and the National Drug Strategy.
4. Established processes for the commissioning of research to guide specific aspects of the national response to hepatitis C.
5. Recognition of the important role of social research in improving the design and delivery of interventions.
6. Adequate surveillance mechanisms.
7. Mechanisms or processes to encourage dialogue between social researchers and people involved in the design and delivery of education and prevention initiatives, to allow for the identification and refinement of research questions, the dissemination of findings, and translation of the findings into practice.

Challenge 4 - Extending partnerships

1. A partnership approach at all levels, with priority given to extending and supporting affected communities' participation.
2. Establishment of structures and processes at national and State and Territory levels that facilitate stakeholders' contribution to policy and strategy development and decision making (see also challenge 5).
3. User groups and hepatitis C councils, appropriately resourced on a recurrent basis, in each State and Territory.
4. Each State and Territory hepatitis C strategy having a component that accommodates the need to build intersectorial partnerships.
5. Demonstrated effort at national and State and Territory levels towards building an integrated approach to the public health challenge presented by hepatitis C, involving the National Drug Strategy and law reform. A bipartisan political approach is necessary to support these efforts.



Challenge 5 - Clarifying structures, roles and responsibilities

1. Advisory and coordinating mechanisms at national and State and Territory levels with capacity for a dedicated focus on hepatitis C.
2. A new strategic document on hepatitis C that provides a framework for the development of more detailed action plans by all jurisdictions, including the Commonwealth.
3. National mechanisms for monitoring progress and supporting the partnership to overcome obstacles to attaining identified goals and, in each jurisdiction, mechanisms for monitoring implementation and progress towards goals. These mechanisms would be existing structures.
4. User groups and hepatitis C councils, appropriately resourced on a recurrent basis, in each State and Territory (see also challenge 4).
5. Adequate funding to support activities that flow from the strategic approach.
6. Inclusion of hepatitis C outcomes in Public Health Outcome Funding Agreements between the Commonwealth and the States and Territories.
7. The National Public Health Partnership to extend its leadership role in promoting integration across national strategies by establishing an Integration Working Party consisting of representatives of both the hepatitis C and National Drug Strategy policy areas. The Working Party should identify areas for increased collaboration and consistency, so that efforts in the two areas enhance and support one another. This commitment to integration should be reflected through formal mechanisms at the State and Territory level.

Directions and priorities

The central recommendation of this review is that Australia develop a national strategy for taking action in relation to hepatitis C. This should be done as a matter of urgency, and the strategy document should have three main functions:

- to define the directions and priorities for taking up the challenges identified by this review
- to form the basis for implementation of the essential components of an organised national response to hepatitis C, as identified by this review;
- to clarify the structures that will be used to implement the Strategy and the respective roles and responsibilities of all elements of the partnership.

Chapters 10 to 13 outline recommended directions and priorities. These should be used as the basis for development of the strategy for redressing the problem of hepatitis C.

The analysis of the different models for configuring Australia's response to hepatitis C (including separate hepatitis C and HIV/AIDS strategies; further development of the 'HIV/AIDS and related diseases' approach; or a communicable diseases framework that takes in specific sub-strategies) suggests there is much to be gained from integrating the approach to hepatitis C with the approach to other communicable diseases where there is substantial cross-over and where efficiencies can be achieved and synergies exploited.

One risk of such integration is, however, that strategies can become over-generalised. It is essential that any strategy dealing with hepatitis C clearly define how the challenges specific to that disease will be met.

This clear definition is lacking at present, and without it significant progress will probably not be made. Placing hepatitis C within a communicable diseases framework must be done in such a way as to allow for the description of strategic approaches specific to hepatitis C (and other diseases) within an overall, integrated framework.

Historically, the response to hepatitis C has been developed within a disease framework. It is, however, well recognised that the main route of transmission of the virus is unsafe injecting by drug users. It is therefore reasonable to expect that the way Australia responds to illicit drug use will have a powerful influence on the future course of the hepatitis C epidemic.

It is essential that the prevention of transmission hepatitis C be seen as part of the 'core business' of the National Drug Strategy.

Any strategic initiatives and arrangements emerging from this review must be very closely monitored in terms of their effect in meeting the five challenges, especially that of reducing the number of new hepatitis C infections, and in relation to the social and economic effects of hepatitis C. This is particularly important in the absence of dedicated funding.

If Australia is to respond effectively to the epidemic, each of the challenges must be confronted and overcome.

Recommendations

1. The reviewers recommend that, in close consultation with the States and Territories, community-based organisations, health professionals and other interested parties, the Commonwealth Department of Health and Aged Care develop a National Hepatitis C Strategy. The Strategy document should clarify four central elements:

   * the directions and priorities for taking up the challenges identified by this review;
   * the essential components of an organised national response to hepatitis C, as identified by this review;
   * the structures that will be used to implement the Strategy and the respective roles and responsibilities of all elements of the partnership;
   * mechanisms, developed cooperatively by funding bodies, for monitoring and evaluating progress with implementation, the data obtained being used for program improvement and accountability purposes.

2. The reviewers recommend that the National Hepatitis C Strategy be developed and placed within the framework of a strategic response to other communicable diseases, so as to maximise efficiencies and exploit synergies. The Strategy should, however, recognise that in some areas disease-specific approaches are needed to respond to particular challenges. Thus the overall framework must allow for the development of pathways that are tailored to particular diseases.

3. Considering that patterns of injecting drug use will have a powerful influence on the future course of the hepatitis C epidemic in Australia, the reviewers recommend that prevention of transmission hepatitis C be seen as part of the 'core business' of the National Drug Strategy.

4. The reviewers recommend that those responsible for implementation of national communicable diseases strategies and the National Drug Strategy, as well as the National Public Health Partnership, give consideration to the development of mechanisms that will lead to a high degree of integration between the national responses to hepatitis C and illicit drugs. This should include consideration of the establishment of an Integration Working Party.

- Reprinted with thanks from the report, *Hepatitis C: a review of Australia's response*, Commonwealth Department of Health & Aged Care.

My combo story so far

I'm currently starting my fourth week of PEG interferon/Riba. I take, 4cc pegylated interferon once a week and 6 capsules of Riba daily. With the PEG I've noticed that FOR ME the side effects are minimal.

I took my shot Tuesday night and if it weren't for the fact that I gave it to myself, I wouldn't have believed that I got a shot. No sides at all. In fact I had a very lively, productive day on Wednesday.

Now this doesn't happen all the time... but it sure was nice to not feel tired. I, too, am a genotype 1b and my Hep God has very high hopes for me to be rid of this dragon.

I want to live a long productive life... not one that keeps me on the sofa or in bed all the time. I therefore chose to try the PEG study.

Forty eight weeks of medication is a small price to pay for a possible remission. I know there can be long term effects from this: thyroid problems, diabetes, etc. but to me it's worth the risk.

Those things can be treated.

My best wishes are with you... as are my prayers that you make the right choice for you.

Benee from Michigan

- Taken from the internet email list: HEPV-L

(model/s used above)

Side effects of interferon in chronic hepatitis C

By G Dusheiko

Alpha interferon is administered by *subcutaneous* [under the skin layer] or *intramuscular* [into muscle tissue] injection either daily or three times weekly for a period of 6 to as long as 24 months. A wide array of adverse effects of alpha interferon have been observed and described in research papers.

Several side effects such as fever, headache, fatigue, *arthralgias* [joint pains], and *myalgias* [muscle pains] are common; especially with the initial injections. These early side effects of interferon are predictable and are encountered in the majority of patients. They may not require dose modification, but can be problematic for a significant proportion of patients.

Other adverse events effects may require dose modification or even discontinuation of therapy in 2% to 10% of patients.

Neuropsychiatric [psychology dealing with nervous system] side effects such as depression and irritability can be most troublesome; their mechanisms are not well understood.

[Certain] blood cell counts decrease during treatment, but the decreases are usually mild, although they can be dose limiting if cell counts are low initially.

Interferon has important immunomodulatory properties, and treatment can induce autoimmune phenomena, the most frequent being autoimmune thyroiditis with either hypothyroidism or hyperthyroidism, especially in predisposed patients.

Other autoimmune disease can be aggravated by interferon therapy. Severe and even life-threatening side effects of interferon occur in 0.1% to 1% of patients; these include thyroid, visual, *auditory* [hearing], *renal* [kidney], and *cardiac* [heart] impairment, and *pulmonary interstitial fibrosis* [damage to lung tissue]. Some of these side effects may be irreversible.

Higher doses of interferon (above 5 million units three times weekly) cause higher rates of adverse events than standard doses. Contraindications to alpha interferon have been recognized.

Author: DUSHEIKO G, ROYAL FREE HOSP, SCH MED, DEPT MED, POND ST, HAMPSTEAD, LONDON, ENGLAND

HEPATOLOGY 1997 SEP;26(3):S 112-S 121

- Above article abridged from an HEPV-L internet email.

Cryosurgery: freezing liver tumours to death

While highlighting that few people with hepatitis C will go on to develop liver cancer, it is very heartening to observe developments in the possible treatment of this serious condition.

Two new preliminary studies from the John Wayne Cancer Institute suggest that when conventional therapies fail, attacking lethal liver tumours by freezing them to death can prolong the lives of terminal cancer patients and possibly offer a cure.

It can also provide dramatic relief of debilitating pain and other symptoms that are caused by a specific type of cancer.

The first study examined 19 patients who had failed conventional treatments such as chemotherapy and received cryosurgery for advanced neuroendocrine cancers that had spread to the liver (neuroendocrine means both the nervous system and any glands that secrete hormones directly into the bloodstream - eg. thyroid, ovaries, testes).

These cancers begin in the small bowel or pancreas and when they reach the liver, the patient can suffer severe abdominal pain, nausea and diarrhoea.

"Typically with advanced disease, patients that do not respond to chemotherapy rarely survive more than a year and die a miserable death," said John Wayne Cancer Institute surgeon Anton Bilchik, M.D., Ph.D., author of both studies.

After cryosurgery patients were free of debilitating abdominal pain, nausea, diarrhoea and other significant symptoms for an average of 10 months, as opposed to being homebound or bed-ridden which is a common condition for people with metastatic neuroendocrine tumours.

"Relieving these people of these terrible symptoms is a tremendous benefit that we've never been able to offer before to people who don't respond to conventional therapy," Bilchik said.

Cryosurgery is performed on these patients by inserting hollow steel probes into liver tumours and filling them with liquid nitrogen at 319 below zero degree Fahrenheit. The super cold liquid turns the tumours into solid balls of ice within several minutes, causing the cancer cells to freeze to death and explode. The harmless dead cell fragments are then absorbed by the body over the next several weeks.

Bilchik said it is likely that reducing the tumour mass is responsible for the reduction of symptoms in these patients. There was an 80 to 90 percent reduction in tumour marker levels after cryosurgery.

"Tumour marker levels often indicate the amount of tumour mass in the body. Lower levels mean less tumour tissue," Bilchik explained. "Interestingly, patients who were resistant to chemotherapy before cryosurgery, afterwards began to respond to chemotherapy after freezing reduced the size of the tumours.

"We have been using cryosurgery to treat livers that have been invaded by cancers that started in the colon and where conventional surgery could not be performed. Now, we are discovering that cryosurgery is a useful tool in treating other cancers that have spread to the liver, such as melanoma."

The second report looked at 20 patients with primary liver, breast, melanoma, ovarian and thyroid cancers with the spread confined to the liver. Seventeen had a significant decrease in tumour marker levels following cryosurgery.

It appears survival was also prolonged, since the median duration of survival was 32 months following cryosurgery. Typically these patients survive less than six months. A new cancer vaccine has been developed at John Wayne Cancer Institute for these patients with promising results.

"The findings of both studies are exciting because we now have a new tool to help many patients live longer and feel better. And in some cases, we may be able to offer a cure," Bilchik said.

(SOURCE: Doctor's Guide to Medical News - September 9, 1997)

- Taken from the internet email list: HEPV-L

Cutting edge treatment trial

Each day we receive internet e-mails describing research into hepatitis C, some of which sound so MICROBIOLOGICAL as to appear bizarre - eg. *"The transmembrane domain of HCV glycoprotein E1 is a signal for static retention in the endoplasmic reticulum".*

Other research news is more relevant to us. One recent email outlines new research into using an obscure vaccine as a treatment for viral hepatitis.

"A preliminary report of a controlled trial of MTH-68/B virus vaccine treatment in acute hepatitis B & C: a phase II study".

This study was carried out by researchers at the United Cancer Research Institute, Alexandra, in Vancouver, Canada.

It involved 84 people, of whom 43 had hepatitis B, and 41 had hepatitis C.

Within each of the above groups, roughly half were treated by being infected with a "deactivated" version of the Bursal Disease Virus (MTH-68/B). The remaining half of each group received 'conventional therapy' (interferon, we'd assume).

In regard to the hepatitis C groups, researchers found that there were a greater number of patients who progressed to 'active' hepatitis on conventional therapy than in the vaccine treated group (26% v. 9%).

The researchers suggest that deactivated viruses that don't cause illness may be of benefit for people with viral hepatitis B & C infections.

It is not known if this study will lead to further research into treatment with deactivated viruses. On its own, it should be considered simply for its curiosity value. Such trials are usually only the first step on a long arduous process that would normally involve a series of large international trails lasting several years.

- This study was reported in full within the journal, Anticancer Research 1998 Mar-Apr; 18 (2B) : 1279-82.

Its not all that bad

I cannot put into words the feelings I get when I read your "Review" booklelts.

Joy at knowing there is support; relief at learning its "not all that bad" and a quality of life can be obtained, etc.

I will be booked into a liver biopsy this month and I'm learning that patience is a daily battle.

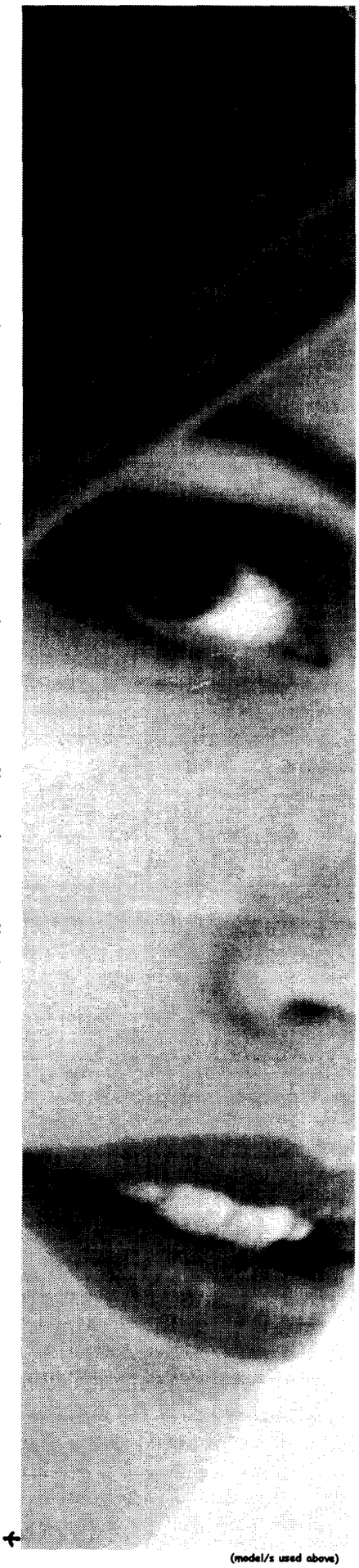
Please keep informing us all of interferon trials and especially side effects.

I read all of the letters sent by readers like me and am keen to hear what people thought of their experiences on interferon.

Yours

faithfully,

Caroline.



(model/s used above)

Interferon side effects: some finer details

Common side effects of *interferon* (IFN) treatment include depression, *paraesthesia* (tingling or crawling of the skin), impaired concentration, amnesia, confusion, and anxiety.

Others include flu-like symptoms such as chills, fever, malaise, *myalgias* (muscle pain), and anorexia; sexual dysfunction such as *alibido* (lack of sex drive or response to sexual stimulus), failure to gain erection or failure to orgasm; mild dementia with apathy and decreased motivation; and cognitive dysfunction such as memory loss, apathy, and a slowing down of mental processes.

These symptoms are rarely severe and appear to be dose related and reversible. On rare occasions, *acute* (short term) mental status changes, including delirium, psychosis, and *neurologic* (nervous system) syndromes will occur.

The significance of these side effects increases, however, when they are *chronic* (long term) and markedly impact quality of life in people who are otherwise relatively well.

Impairment of *cognition*: (thought, perception & reasoning ability)

Even after a single dose of 0.1 MU of IFN, normal healthy volunteers report subjectively reduced alertness. A single dose of 1.5 MU results in slowed performance on a reaction time test 6 and 10 hours after injection.

Toxicity develops after several weeks of chronic IFN therapy and includes subjective complaints of memory loss, depression, lack of initiative, and generalised slowing of thought process.

Most studies report the resolution of symptoms within 2 to 3 weeks following therapy. However, some people develop side effects that persist after treatment discontinuation, without any intervening change in their disease status.

Most studies report the resolution of symptoms within 2 to 3 weeks following therapy

Mood disorders/depression:

The distinction between levels of depression is based on the intensity and duration of depressive symptoms; the presence or absence of associated physical, emotional, and cognitive symptoms; and the course of symptoms over time.

The actual rate of IFN-induced depression is unknown. When cancer patients treated with IFN complain of depression, they typically mean apathy, fatigue, and slowing of mental capabilities. Some people will experience *dysphoria* (feeling ill at ease and restless) at the beginning of treatment, with onset of other symptoms. For others, dysphoria comes later, possibly because cognitive symptoms become more severe or difficult to tolerate.

These people also may experience other psychological symptoms typical of major depression, including *anhedonia* (lack of pleasure with previously pleasurable acts) and helplessness. In vulnerable people, symptoms may become more difficult over time or with dose escalations, leading to dose modifications or temporary discontinuation.

There are multiple possible mechanisms by which IFN may cause *neuropsychiatric* (a psychological approach dealing with the nervous system) side effects; unfortunately, little of which is well understood.

Assessment:

All people treated with IFN should be considered at some risk for development of an *affective syndrome* (mood swings), and for cognitive side effects as well. Although there is no standard method for assessing IFN induced depression, pre-treatment assessment should be done so that changes can be reliably detected and documented.

People at risk:

Evidence of current or past depression should not be automatic grounds for exclusion from IFN therapy, but does suggest that the person would be at higher risk for side effects. People currently treated with antidepressants should be monitored for needed dose adjustments or medication changes.

Treating side effects:

Attempts to lessen or prevent IFN-induced psychological side effects have been hindered by a number of factors, including lack of recognition of the problem, a poor understanding of how psychological side effects are caused, and a lack of scientific trials of *pharmacological interventions* ('pills & potions' to prevent side effects).

To intervene effectively it is first necessary to raise a person's awareness of the possible problems. Discussion of possible side effects should take place before initiation of treatment.

People treated with IFN are sometimes reluctant to complain of depression or impaired cognitive function. This may be due to the stigma associated with psychiatric illness, or because they fear that they will be given a lower dose or be taken off therapy entirely.

Some people who complain of mood or cognitive side effects can be instructed to either "pace" themselves or alter their demanding work and recreational schedules to help maintain some reasonable amount of participation in normal activities.

For others, these interventions, which often are viewed as concessions, do not help and only add to their frustration and dissatisfaction.

Fatigue and depression encourage sedentary *(low physical activity)* behaviour that can be self-reinforcing, and people who are not active should be encouraged to maintain some level of physical activity.

In the event of suicidal ideations, delusions, or panic, therapy should be discontinued, and the use of anti-psychotic medications may be useful. Whether it is prudent to resume therapy in these cases is a matter of clinical judgment, although it is probably advisable to reduce the dose of IFN and closely monitor side effects.

Pharmacological interventions:

'Pills and potions' to address IFN-induced depression have not been formally studied in controlled clinical trials; however, a number of medications are currently used, and the lessening of psychological side effects appears to be a realistic goal. At least three classifications of drugs have shown some use.

Antidepressants:

Although single case reports have documented successful use of fluoxetine and nortriptyline in people treated with IFN for hepatitis C, there have been no published studies of the value of antidepressants commonly prescribed for IFN- induced depression.

In the cancer treatment setting, we have used *SSRIs* (selective seratonin receptor inhibitors) with some success in individual people. These medicines may counteract IFN-induced decreases in serum serotonin levels. Antidepressants, such as fluoxetine, may be advantageous because they also may improve the cognitive and behavioural slowing associated with IFN toxicity.

Tricyclic antidepressants are relatively more sedating than SSRIs. These medications increase levels of norepinephrine and, for many, serotonin. The anti-muscarinic effects of some tricyclic antidepressants can aggravate memory dysfunction secondary to IFN therapy itself.

Opioid *antagonists*:

To date, the only study to evaluate opioid antagonists (a drug that opposes the effect of another) in this setting has investigated the opioid antagonist Naltrexone. The majority of people in this pilot study experienced partial or complete resolution of psychological symptoms; however, a consistent domain of psycholgical improvement could not be identified.

Psychostimulants:

The use of psychostimulants to treat secondary depression is increasing. Methylphenidate is currently being investigated to treat IFN neurotoxicity. Their mood-elevating effects could be caused by their neurochemical activity or by a beneficial psychological reaction due to increased energy and improved concentration.

- This article is abridged from an internet email list (HEPV-L) post of selected quotes from "Mood & Cognitive Side Effects of Interferon-alpha Therapy", Seminars in Oncology, Vol 25, No 1, Supplement I (February), 1998, pp 39-47 by A. D. Valentine, et al.

  This can be found on the website: http://www.hepatitis-c.de/feb99.htm

Many thanks to our *Medical & Research Advisory Panel* for their review of the material.

(model/s used above)

Impact of alcohol on the histological and clinical progression of hepatitis C infection.

In people infected with the hepatitis C virus (HCV), 20% to 30% will progress to cirrhosis in over two to three decades. Viral and *host* (human) factors that are important in the *clinical progression* (relating to symptoms and course of disease) and *histologic progression* (relating to damage of tissue structure) of HCV infection are not entirely certain.

It has been suggested that liver disease is worse in alcoholics infected with HCV. In a *retrospective study* (looking at past & existing cases), researchers at the University of Illinois at Chicago Medical Center (USA) examined the effect of moderate alcohol intake on the histologic and clinical progression of HCV infection. They assessed whether other variables also independently impacted on disease progression - such as gender, length of exposure, mode of contracting HCV, viral load levels, and *ferritin* levels (a stored form of iron in body tissue).

Liver biopsies were analyzed for the degree of fibrosis, presence of cirrhosis, and histologic activity by using Knodell's *Histologic Activity Index* (a method of assessing and recording liver tissue damage).

People were divided into two groups based on whether their alcohol intake was significant or not significant.

Significant alcohol intake was defined as women drinking more than 8 standard drinks per day, and men, more than 12 standard drinks.

The groups were further divided based on the decades of exposure to HCV.

Researchers found there was no difference in the age or length of exposure to HCV in the alcohol and the alcohol-free group. HCV viral load levels, ferritin levels, and viral genotypes were also similar in both groups.

The histologic and clinical acceleration of liver disease was independent of the mode of exposure or sex.

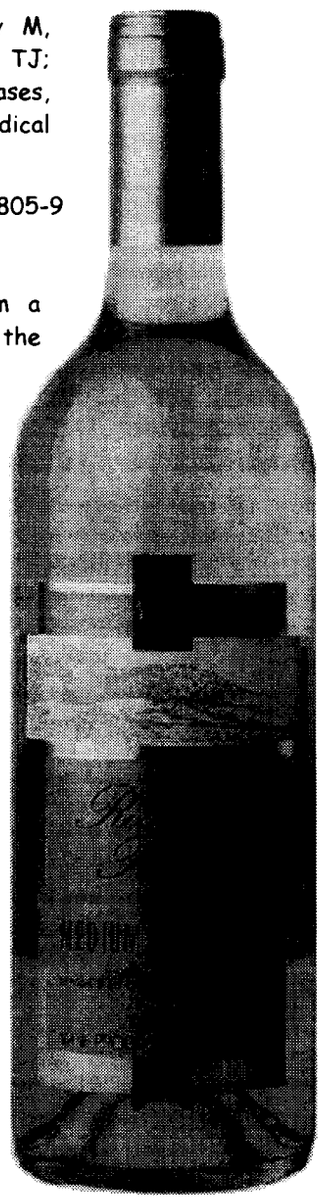
There was a two- to threefold greater risk of liver cirrhosis and *decompensated liver disease* (see below) in the alcohol group. Also, the rate to which people developed cirrhosis was faster in the alcohol group with 58% experiencing cirrhosis by 20 years as opposed to 10% in the nonalcohol group.

In summary, the researchers concluded that alcohol intake is an independent risk factor in the clinical and histologic progression of HCV infection.

Researchers: Wiley TE, McCarthy M, Breidi L, McCarthy M, Layden TJ; Section of Digestive and Liver Diseases, University of Illinois at Chicago Medical Center (USA).

Source: Hepatology 1998 Sep;28(3):805-9

- This article is abridged from a research abstract taken from the international email list, HEPV-L.



* **Decompensated liver disease:** Our livers can often endure a considerable amount of cirrhosis (scaring of liver cells) before their ability to carry out their normal functions is affected.

The term *decompensated liver disease* refers to when the level of damage has started to interfere with the liver's ability to function properly (as shown by blood tests like albumin, prothombin and bilirubin) and is causing severe illness (weight loss, fluid retention, stomach swelling, bleeding problems).

+

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

Future directions in treatment of chronic hep C

Hepatitis C virus (HCV) infects over 170 million people worldwide. While interferon is currently the most used single agent therapy, this drug may result in a sustained loss of virus from the blood in only up to 15% of patients; new options for treatment are needed.

With the release of ribavirin in North America and Europe, a viral clearance rate or 'cure' may be attained in up to 40% of patients.

Developing successful antiviral therapy that prevents or delays the development of cirrhosis, liver failure and liver cancer as well as decreasing the demand for liver transplantation are clearly identified goals.

Unfortunately, there is no complete in vitro model of HCV replication or translation. Due to the lack of an animal or cell culture model of HCV infection, in vitro translation screening systems to identify inhibitors of HCV protein translation are being evaluated by a large number of biotechnology companies.

With advancing computer technology, high throughput screening processes are now possible and can be joined to specific in vitro model testing systems. Along with examining some of the information known about HCV therapy and the HCV genome, the present review discusses potential targets for new therapies and identifies therapeutic agents that are nearing clinical application.

Researchers: Gish RG, Department of Medicine, California Pacific Medical Center, San Francisco, USA

Source: *The Canadian Journal of Gastroenterology* Jan-Feb 1999;13(1):57-62.

- Taken from the internet email list HEPV-L

To access a full copy of the above mentioned report, contact your local university library. Ask if they subscribe to the *Canadian Journal of Gastroenterology*. If they do, quote the above reference.

Costs of HCV infection

Recent studies have estimated the costs of hepatitis C infection in Australia, with researchers considering both the direct costs and, for the first time, the indirect costs relating to the hepatitis C epidemic.

Direct costs are those associated with medical and public health action taken to tackle specific aspects of the disease, and include monitoring, research, prevention, testing, treatment and palliation.

Indirect costs are those relating to the loss of production in the workforce that results from premature death and ill health.

In addition to direct and indirect costs, researchers estimated financial burden in terms of *prevalence based* (current costs for people who already have HCV) and *incidence based* (estimated costs of new infections occurring in the future).

By nature, economic modelling is usually conservative and the following figures may represent the lower estimates of actual cost.

Prevalence based direct costs for 1996/97 were estimated at $75 million. It should be noted though that a number of direct cost categories, such as personal costs, state reference laboratory and government administration costs, were excluded from the research.

Prevalence based indirect cost for 1996-97 was estimated at $32.5 million.

Incidence based direct costs (lifetime costs incurred by a set number of people catching hepatitis C at the same time) show that the currently estimated cost of hepatitis C in 1,000 newly infected people amounts to nearly $13 million over 50 years. Put another way, the average lifetime direct cost of hepatitis C per person is calculated to be at least $13,000 - a figure that is close to earlier estimates.

Incidence based indirect cost associated with a cohort of 1,000 newly infected people is currently estimated at $33.6 million.

Thus total conservatively estimated costs per case of HCV infection per lifetime amounts to just less than $50,000.

Thus the currently estimated total lifetime cost for people already with HCV amounts to $10 billion (200,000 people x $50,000). Additionally, the estimated 11,000 new cases of HCV transmission occurring each year add a total lifetime cost of $550 million, annually.

It is estimated that 2,000 HCV infections are prevented each year by existing needle & syringe programs and education efforts - saving at least $12 million in health costs annually. It's not surprising that economists have found existing needle and syringe programs represent a "blue-chip investment" offering large health gains, financial savings, and other preventative benefits at very low risk. Treatment with interferon offers a reasonable health return, albeit with some uncertainty or risk associated with treatment side effects and quality of life.

- *Economic analyses relating to hepatitis C,* Alan Shiell in *Hepatitis C: a review of Australia's response.* Chapter 7: 83-96. Prepared by David Lowe and Ruth Cotton for the Commonwealth Department of Health and Aged Care, January 1999.

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 Helpline *on 9332 1599 (Sydney callers) or 1800 803 990 (NSW callers).*

An update: research & other projects

Federal Health & Aged Care Minister, Dr Michael Wooldridge, awarded a total of $1 million to twelve hepatitis C research projects.

The projects are designed to identify strategies that will slow the spread of hepatitis C and improve the quality of life for people with HCV.

The following research projects were chosen by a joint committee of the National Health & Medical Research Council (NHMRC) and the Australian National Council on AIDS & Related Diseases (ANCARD).

Responding to advertisements in major daily papers, the committee received 68 initial applications for funding. From these, 31 were short listed and then the final 12 were selected.

The Commonwealth Department of Health and Aged Care announced that the research funding forms part of a National Action Plan - providing a framework for government and community efforts to reduce the impact of HCV.

1. *An intervention to improve compliance with skin penetration guidelines in tattooists, beauty therapists and hairdressers*

   Jill Cockburn, et al. University of Newcastle, NSW, $75k

2. *A pilot peer-based hepatitis C counselling and testing service at a needle & syringe program*

   Nick Crofts, et al. Centre for Harm Reduction, Macfarlane Burnett Centre, VIC, $70k

3. *Prevention of hepatitis C infection amongst injecting drug users of Vietnamese ethnicity*

   Nick Crofts, et al. Centre for Harm Reduction, Macfarlane Burnett Centre, VIC, $95k

4. *Quality of life among people living with chronic hepatitis C infection*

   Michael Dunne, et al. Queensland University of Technology, $75k

5. *Identifying the social, personal and health needs of women living with hepatitis C*

   Sandra Gifford, et al. Deakin University, VIC, $135k

6. *National survey of GPs about needs, outcomes and patterns of care*

   Leena Gupta, et al. Central Sydney Area Health Service, NSW, $45k

7. *Risks for hepatitis C: transition and initiation to injecting drug use among youth in a range of drug user networks*

   Susan Kippax, et al. National Centre in HIV Social Research, NSW, $165k

8. *Exploring testing injecting drug users for hepatitis C and HIV/AIDS*

   Wendy Loxley, et al. Curtin University of Technology, WA, $42k

9. *National survey of hepatitis C risk practices among injecting drug users: an overview of risk practices and their context*

   Greg Rumbold, et al. Turning Point Alcohol & Drug Centre, VIC, $130k

10. *Reducing transmission of hepatitis C in high risk young people: a peer education strategy*

    Susan Sawyer. Royal Children's Hospital Research Institute, VIC, $65k

11. *Feasibility study of non-injecting routes of administration among intravenous drug users*

    Alex Wodak, et al. National Drug & Alcohol Research Centre, NSW, $60k

12. *Gay men, drug culture and hepatitis C prevention*

    Gary Dowsett. Australian Research Centre in Sex, Health & Society, VIC, $60k

Other NSW projects

Other non-research hepatitis C projects (not connected to the above funding grant scheme) have been initiated here in NSW. These are funded through a joint Commonwealth/State scheme (called Public Health Outcome Funding Agreements) and include:

1. *Review of care & treatment needs of people with HCV*

   NSW Health Department, $60k

2. *NSW healthcare worker education project*

   Hepatitis C Council of NSW, $100k

3. *Non-English speaking information & support project*

   Multicultural HIV/AIDS Service, $100k

4. *NSW Public Awareness Campaign*

   NSW Health Department, $600k

5. *NSW school-based education project*

   Consultant to be confirmed, $100k

6. *Review/development of HCV education resources project*

   Centre for Education & Information on Drugs & Alcohol, $100k

Other Commonwealth projects

Other hepatitis C projects, not connected to the $1 million grant scheme mentioned above, have been in place or will be initiated by the Commonwealth Department of Health & Aged Care and/or ANCARD. These include:

Hepatitis C GP Education Project, (targeting GPs, Royal Australian College of General Practitioners).

Australian Reference Centre for Hepatitis Information, (targeting healthcare workers, operating out of the Albion St Centre, NSW).

National Hepatitis C education & prevention program for people who use drugs illicitly, (undertaken by the Australian Intravenous League).

Education for people living with hepatitis C, (undertaken by the Australian Hepatitis Council).

HCV adult learning website & education manual for healthcare workers, (Queensland Medical Education Centre, University of Queensland).

Prevention initiatives: National HCV Prevention Initiatives Reference Group, (update, modification & distribution of existing prevention resources, undertaken by Queensland Health Dept).

It is envisaged that further research projects will be instigated under the ANCARD Commissioned Research Grants scheme.

Hepatitis C and the Premier's Drug Summit

The Hepatitis C Council has urged the Premier, Minister for Health and all delegates to the 17-21 May Drug Summit in the NSW Parliament to pass resolutions that will help reduce the unacceptable number of new HCV transmissions occurring across NSW and the whole of Australia.

Around 11,000 new HCV infections occur each year - that's over 30 per day - in Australia, with almost half estimated to be in NSW. Ninety percent of new transmissions are as a result of blood-to-blood contact caused when people share equipment used to inject illicit drugs.

The recent NSW Parliamentary Inquiry report, *Hepatitis C: The Neglected Epidemic*, made wide reaching recommendations to help bring about major reductions in new HCV transmissions.

The report considers harm minimisation to be the most effective underlying principle for strategies to prevent the transmission of hepatitis C among injecting drug users, and the Council strongly supports this view. It is on this principle which all recommendations directed at people who inject drugs are made - both in the general community and in the state's correctional system.

The Council has urged the Drug Summit to give priority attention to three recommendations:

1. That needle and syringe programs (NSP) are noted as being effective in helping prevent HCV and other blood borne virus transmission, and that they should be funded to enable expansion in terms of equipment provided, education and information supplied, hours of opening, integration with community health programs, education for health care workers within NSPs and that police be instructed on NSPs roles and allow clients unhindered access to them;

2. That the Minister for Health establish a *NSW Intersectoral Advisory Committee for Hepatitis C* and invite the Ministers for Corrective Services, Juvenile Justice and Police and the Attorney General to join him on the Committee. This Committee would consider the role of drug policy and law reform as a pragmatic measure to limit the transmission of hepatitis C;

3. That the Premier invite his Parliamentary colleagues, from both Houses and all political parties, to form a *Hepatitis C Parliamentary Liaison Group.* Its role would be to advocate and support hepatitis C related policies within the political domain, with an overall objective to limit the spread of hepatitis C in the general community and the corrections system.

Needle and syringe programs have been shown to be effective in reducing the prevalence of hepatitis C in people who are new to drug injecting, and they play a vital role in providing education and information to people so that health related harms associated with drug use are minimised (see *Costs of HCV infection*, p27).

What is a cure ?

By Professor Graham Cooksley

The dictionary defines 'cure' as being "a healing or restoring to normal". Such definitions are vague in today's precise terminology. The terms we use are:

* "sustained biochemical response" - normalisation of alanine aminotransferase (ALT) for six months following the end of treatment. This means that on-going liver damage has ceased
* "sustained virological response" - this means the absence of virus by Polymerase chain reaction (PCR) six months after cessation of therapy
* "histological response" - which means improvement by two units on the HAI [liver biopsy] score.

  [For more info on 'response', see Ed23, p16; for 'biopsy', see Ed20, p28]

These responses above can be measured very precisely but need to be interpreted with intelligence other than blind acceptance.

An ALT just below the upper level of normal can still have some minor liver damage going on if we were to do a biopsy.

The PCR is sensitive down to low levels that may vary from less than 100 viral particles per ml to less that 1,000 viral particles per ml, compared with the usual circulating viraemia in a patient with chronic hepatitis C of about 1,000,000 particles per ml. Thus a negative PCR does not mean "no virus", it means exactly what it says, that the virus level is less than a very low level, but may not be absent.

The histological improvement may take up to a year to evolve, with continued improvement in that time, so the timing [of a liver biopsy] relevant to the change in virus levels or ALT is clearly important.

Furthermore, cirrhosis does not occur overnight and the liver biopsy therefore may reflect some variation, depending on the site of the sample from the liver.

These clear definitions are required by regulatory authorities such as the Food and Drug Administration (FDA) to apply to populations being treated and referee for journals in the scientific literature. They may not apply as well to individual patients.

We do have to make some inferences from them, however. For example, patients relapse early, and more than 90% of patients who relapse will relapse within the six months following cessation of treatment. However, some patients may relapse after this time, so that everybody in a trial who has responded at six months cannot be given a watertight guarantee that they will never relapse.

This, however, does not mean that most patients will relapse, indeed quite the contrary. This statement applies to both virological and ALT responders. To confuse matters, even patients with very low levels of virus following treatment may still respond. A long-term follow-up study has shown that patients with very low levels of virus may get decreased levels with eventual disappearance.

Note that cirrhosis will never return to normal, so that even if you have total eradication of the virus and the inflammation of the liver ceases, the cirrhosis will remain with its attendant complications. Thus you can cure your chronic hepatitis C but not your cirrhosis.

In the case of hepatitis C the most we can hope for is loss of virus and no further liver damage. This would be regarded as a cure.

At the end of the day what really matters is whether there is an absence of morbidity (symptoms of illness) and mortality (chance of serious illness leading to death).

Such a study would require following patients for the rest of their life, and is clearly impractical. Thus we rely upon surrogate markers such as liver damage biochemically and histologically and the presence of virus as demonstrated on PCR.

In the case of hepatitis C the most we can hope for is loss of virus and no further liver damage. This would be regarded as a cure.

On the other hand if you have cirrhosis nothing will cure that unless you have a liver transplant. However, although that might fulfil the criteria of restoring to normal ie non-cirrhosis, it would not be by the process of healing and whether you would regard it as normal to take immunosuppressants for the rest of your life is also questionable.

Furthermore, there may be drugs in the future that would prevent the virus doing any damage, even though we didn't eradicate it. If you had a form of treatment that prevented liver damage, it wouldn't matter how much virus you had circulating. This phenomenon occurs in patients with chronic hepatitis B who have acquired it perinatally *[during pregnancy or shortly afterwards]* and lasts for about two decades. Because the body is immuno-tolerant of the hepatitis B virus there are very high levels of circulating virus but no liver damage occurs.

There are also many viruses that may circulate at low levels. That may sound bad to you, but it may be compatible with a perfectly normal life, eg we have all been exposed to the Herpes virus (cold sores) but to the vast majority we never have further problems. Ditto with the Varicella virus and the measles virus.

- Graham Cooksley is Director of the Clinical Research Centre, Royal Brisbane Hospital.

  Abridged with thanks from the Hepatitis C Council of QLD newsletter, *Hep C News*, Feb 1999.

My situation

I was given your brochure *Hep C: what you need to know* in January this year. I found the information enclosed almost answered all the questions I'd been asking over the last 10 years.

I have, only since reading the brochure, realised that the fact that I was diagnosed nonA-nonB, a long time before the hep C diagnosis, means that I have had hep C for a good 10 years plus.

Until now, I thought them separate and believed I'd only contracted the virus 6 odd years ago, not the 11 years that it would add up to since the nonA-nonB, diagnosis.

I was also a VERY heavy drinker from the age of 15 years old, till just recently, as well as continued abuse of all prescription and non prescription drugs throughout the same time period.

I overdosed several times through these years, and was informed more than once, that my liver was suffering damage that bordered on cirrhosis.

Until recently, my psychiatric problems prevented me from caring about any of the warnings I'd been given and so continued to worsen the damage.

I had also suffered a miscarriage at 6 months when I was around 22 and at that point, I was injected with Depo provera which was discontinued due to major hormonal complications.

I have since then had so many problems, starting from a 3 year period without menstruation, to symptoms almost identical to menopause not to mention agonising periods to this day, and mood swings that borderline my old psychotic episodes.

Because of these things I didn't relate any hormonal problems to hep C, and am now worried it could have been the cause all along. I have also had one breast develop an infection 2 or 3 times and now the nipple is permanently inverted and often secretes a smelly substance.

All these things I have mentioned to my new doctor who is currently my methadone prescriber as I've recently moved to the bush and have been on methadone for 2 years and to my surprise, this doctor sent me for the usual antibody test and then, regardless to the severity of my symptoms, told me that the antibody test was negative, therefore my hep C was inactive.

He informed me that the fact I've had it for over 10 years without symptoms and am now suffering all of them, meant nothing if the test was negative.

I cannot get this doctor to pay any attention to my unusually dangerous life history, or believe any of my complaints, I get the impression that he is disregarding everything I say and discriminating against me unfairly.

Personally, I know that THAT stage of my life is well & truly over and now that I haven't had a drink or any pills etc for over 2 years, I have become extremely aware, and anxious about the condition of my body and the quality of the remaining part of my life. Now that I'm lucky enough to live and appreciate that fact, I need to be sure that any damage I HAVE done is either reversed, or minimised.

As I stated already, this doctor has probably seen a majority of people in my position either tell lies or over indulge in their illness in order to have some prescription of the other. This is not the case with my situation and I am genuinely concerned with the deterioration of my health - particularly since my life style has become so extremely healthy - but to no avail.

I don't want to wait till I'm hospitalised to find out what is wrong with my body.

The aim of this letter, other than to tell others of my situation, is to ask if there is some information you could send me, telling me where I can get help on these matters in my area, as I can't find anyone myself.

Thank you, Mel.

[We've put Mel in contact with the NSW Hep C Helpline. *They have recommended some local people that she can contact - Ed]* +

(model/s used above)

The treatment of hepatitis C :
new data suggest more effective treatment regimes

By William Sievert and Robert Batey.

Infection with hepatitis C virus (HCV) is epidemic in Australia and is a common reason for liver transplantation in patients with decompensated cirrhosis [*see below]. Since the description of the virus and development of an HCV-antibody test in 1989, substantial progress has been made in both our understanding of the natural history and the treatment of hepatitis C. However, debate surrounds several issues:

How can we identify the people most at risk of progression to cirrhosis - the logical candidates for antiviral therapy?

What are the most effective courses of treatment and the best methods to predict and monitor treatment success?

Can antiviral therapy prolong survival by decreasing the incidence of HCV-related cirrhosis and liver cancer?

Identifying patients for therapy:

Identifying people for treatment is difficult because of uncertainty in predicting progression to cirrhosis in people with HCV. Utilising liver biopsy is helpful. A recent consensus conference recommended antiviral therapy for people with portal or bridging fibrosis (initial stages of liver cell damage) and moderate necroinflammation (inflammation causing death and scarring of liver cells), as these patients are most likely to progress to cirrhosis, in contrast to those with minimal inflammation or no fibrosis. Additionally, within the acute stage following infection, antiviral therapy is thought to lead to the infection being less likely to become chronic.

The federal government currently funds 12 months of interferon alfa (IFN) at 3 million units three times a week for patients with non-cirrhotic chronic hepatitis C - the prevailing international recommendation for therapy. However, since October 1994, only 3000 Australians have received IFN. This may relate to peoples' questioning of therapy, as IFN commonly causes a "flu-like" syndrome of myalgia (muscle pain), fever and fatigue, can adversely affect mood and concentration, and can cause neutropenia (a blood disorder), thrombocytopenia (a decrease in blood platelets) and thyroid dysfunction.

Therapy outcomes:

Host factors (a person's physical state) and viral factors help predict the probability of a virological sustained response before and during treatment (defined as undetectable viraemia six months following treatment cessation). But is a sustained response really sustained? Can IFN alter the incidence of cirrhosis and liver cancer? (*response*: see Ed 23, p 16).

In 80 responders to IFN followed for four years after treatment, viral RNA (parts of the actual virus) remained undetectable (by PCR) in 96% and liver histology (cell & tissue structure) improved in 94%, which supports the premise that HCV infection can be cured.

Exciting but controversial data (research results) show that IFN therapy is associated with a lower incidence of liver cancer: in 90 patients with HCV-related cirrhosis, liver cancer was detected in only 4% of IFN treated subjects, compared with 38% of untreated patients. Similar and conflicting studies make it unclear if the observed effect is real and, if so, whether it is related to viral elimination or to an independent effect of IFN on fibrosis (an initial stage of liver cell damage) and carcinogenesis (how something causes cancer to develop). However, these data do provide a rationale for treating patients with advanced fibrosis or cirrhosis.

Difficult management decisions arise in people who relapse (ie when treatment fails them), as re-treatment with higher IFN doses is not consistently beneficial, but longer-duration therapy can achieve sustained responses in 20%-40% of relapsers.

The situation is dismal when retreating people who showed no initial response - sustained-response rates range from 0 to 3%. Thus, there has been a strong move to assess combination antiviral therapy.

Combination therapy:

Ribavirin is an antiviral nucleoside analogue (type of drug) that, combined with IFN, can increase sustained response rates. Ribavirin given orally is well tolerated, but has two important side

effects: haemolysis (damaged red blood cells releasing haemoglobin into the bloodstream) and teratogenicity (serious birth defects). Effective contraception in women and men is mandatory during and six months following ribavirin therapy.

A study of combination therapy in relapsed patients reported a virological sustained response in 47% of patients, compared with 5% in patients given IFN alone. Based on this, the United States Food and Drug Administration has licensed the combination of interferon a-2b plus ribavirin for treatment of relapse following interferon monotherapy.

Data are now available from two large studies of IFN plus ribavirin in previously untreated patients. A study of 832 patients from Europe, Canada and Australia showed a virological sustained response in 43% receiving combination therapy, compared with 19% in those receiving IFN alone. Subgroup analysis showed that 64% with HCV genotypes 2 or 3 achieved a sustained response following either six or 12 months' treatment, but patients with genotypes 1 or 4 attained a 31 % sustained response only after 12 months' therapy (*genotypes*: see Ed 23, p 11).

Similar findings were reported from a US study of 912 treatment-naive patients (people who've not had interferon before). Adverse events such as haemolysis, dyspnoea (difficult breathing) and rash were common with combination therapy, but not always treatment limiting.

Customising therapy:

How do we optimise HCV therapy in light of these new data? Should combination therapy be first option in all patients or could some be treated effectively with interferon alone?

Evidence now strongly supports determining genotype, viral load and liver histology before treatment, to select a regime with a reasonable chance of success. HCV RNA testing (PCR) during therapy may allow early cessation of treatment destined to be unsuccessful in particular people.

Current federally funded treatment will be successful in only 30% of patients with genotype 3a, a low viral load and portal fibrosis. Such patients may be better treated with a shorter course of combination therapy.

Those with a more resistant viral profile (genotype 1 and/or a high viral load) and more fibrosis should not receive 12 months of IFN three times weekly alone, as the probability of success is low. Potentially more effective regimens include, either induction (daily IFN dosing) for the first weeks of treatment or combination therapy with induction. Studies show that daily dosing reduces viral load more quickly than the currently recommended thrice weekly dosing.

Combined interferon and ribavirin therapy is currently only available through either clinical trials or compassionate-access schemes. Aushep 6 is an ongoing study of highdose interferon induction with or without ribavirin in people who have tried interferon with no initial response.

Two studies for previously untreated patients are available: Aushep 7 involves two different rates of interferon induction, and Aushep 8 will randomise people by their genotype to ribavirin and interferon with or without an induction course.

Australia will benefit from the optimal treatment of HCV infection - an epidemic that, if unchecked, will expose the healthcare system to increased costs and patients to an increased incidence of liver failure or liver cancer, for which treatment remains largely unsatisfactory.

- (Abridged from the referenced original) Sievert, W & Batey, R. **The Treatment of Hepatitis C.** MJA 1999; 170: 200-202.

  William Sievert is Senior Lecturer in Medicine, Monash University, Monash Medical Centre, Clayton, VIC.

  Robert G Batey is Professor of Medicine, University of Newcastle, John Hunter Hospital, Newcastle, NSW

* **Decompensated cirrhosis:**
Our livers can often endure a certain amount of *cirrhosis* (scarring of liver cells) before their ability to carry out their normal functions is affected. The term 'decompensated cirrhosis' refers to when level of damage has started to interfere with the liver's ability to function properly (as shown by blood tests like albumin, prothombin and bilirubin) and is causing severe illness (weight loss, fluid retention, stomach swelling, bleeding problems).

* **A note from members of our Medical & Research Advisory Panel:**

In regard to 1st paragraph, this column, it is perhaps a strong statement to say that these people should not receive interferon although the comments are sound. Also, combination therapy could be given with or without induction dosage. Studies have not involved induction and show a 35% sustained response."

Hi gang

Recently (Jan 18), there was a segment on Entertainment Tonight about Naomi and Wynona Judd and Mark Steines from ET said this:

"With mother Naomi saying she's cured of Hepatitis C and daughter Wynonna's solo career soaring, the Judd's will have plenty to celebrate."

I rang ET in LA and New York and spoke to a few people who then gave me the producer of that segment's details and I wrote to him asking him to clarify the statement as not only do I have hep C but I am also on the lung transplant list and their story raised HOPE in me post transplant.

Today after finally getting my car fixed, I could get to the post office to receive my parcel, it was from Naomi. She wrote me a letter, sent suggested readings and gave me a beautiful photo autographed:

"Love & Happiness Fran! Naomi Judd 99. Keep your Faith and Share your Hope!"

So here I am sharing with all of you, my wonderful news.

As I was having a completely blond day, forgetting to get $ out to pay for my car, then forgetting the card to get the $ so I had to go home in the taxi and then start again, it was looking like a rough day and I said to the taxi man I should go back to bed. Then I received the mail.

As I sat home reading through the stuff she sent me, I was so happy and teary and thankful to myself, that I kept the letter I wrote and that I did write, then I received a phone call.

It was the hepatitis C Council asking me if I could come in and help with a mailout. I was blown away let me tell you!

Hopefully being the first CF and hep C person to be transplanted in Australia will be something I will be able to share in another letter to Naomi in the future!!!

Stay hopeful everyone and aware, you never know when one comment could enhance your life even if it is from a show like Entertainment Tonight!!!

Love & hope, Fran.

my story

Love from Naomi

The most important weapons you have in battling an illness are hope and knowledge. I know, I've been there. I spent endless hours pouring over materials to educate myself. I hope my journey to self-discovery will benefit you and stimulate you to become proactive. This reading list should get you started so that, through your own research, you may arm yourself with knowledge.

Equally important in your fight against this awful disease is hope. Hope is the most powerful medicine there is. It is my faith and my hope that has kept my head above troubled waters and the very reason that I am alive and radiantly healthy today. I believe that faith and hope are twins born of the spirit. I encourage you to discover your own belief system. I don't use the word religion very much because I think religion is simply a bridge to get us across to our true nature, which is our spirituality. But find the bridge that will connect you to your spiritual self.

In my own battle with Hepatitis C, I chose to make use of the best therapies in modem medicine along side of lifestyle changes and complementary techniques. Coming out of mainstream medicine myself, I believe in using all available modalities. Peace of mind is the goal. It is not the absence of a disease or problem, peace of mind is the ability to deal with conflict. I hope you realize there may not always be a cure, but there can always be healing.

Although I am free of the virus, I will not feel completely free until all my companions are also free of this virus.

Fran's autographed photo of Naomi

Hepatitis through the ages - part 3

Continued from Edition 24, p35

[Our previous two instalments described the early 'discovery' of viral hepatitis within Napoleon's army, and soldiers of the American Civil War. The series went on to outline how the actual viruses that were causing liver illness were identified, and how vaccines were developed. Our previous instalment was describing the discovery of a test for detecting the hepatitis B virus.]

Haemophilia and leukemia patients receive numerous blood transfusions, and people with Down's syndrome have weakened immune systems - perfect conditions for contracting hepatitis. And the disease [hep B] is common in Asia and Africa, which would explain why the Au antigen turned up more frequently there.

In 1966 Dr. Barbara Werner, who had been testing Au samples in the lab, felt ill and tested herself for the Au protein. Sure enough, her blood tested positive. She became the first person to be diagnosed using the Au test.

Saul Krugman sent samples of the MS-I and MS-2 hepatitis infected blood to Dr. Blumberg to see if they contained the Australia antigen. It was not present in the MS-I sample, but it was present in the MS-2, or hepatitis B strain.

Dr Blumberg hadn't identified a hepatitis virus, but he discovered the next best thing - a marker to detect hepatitis B. His work helped to confirm Dr Krugman's discovery that there were two different hepatitis strains, and in turn Dr. Krugman's studies helped scientists understand the significance of the Au antigen.

The World Health Organisation called Dr. Blumberg's discovery "the most spectacular advance in the seemingly insoluble problem of human hepatitis." Baruch Blumberg won a Nobel Prize for Medicine in 1976 for his discovery of the Au antigen.

His discovery opened up the way for the development of a vaccine that would prevent infection and spread of the virus.

Practical applications to save lives

Dr. Blumberg's lab began to reject all Au-positive blood in their studies, and the number of patients who developed hepatitis after transfusions fell by two-thirds. Within a year other hospitals were rejecting HBV-infected blood donations.

A *New York Times* article in July 1970 helped the rest of the medical community to accept the findings. The article said that the virus that causes hepatitis had been found, and that it was being spread through blood transfusions. As the discovery became more widely known, several lawsuits were filed against hospitals by patients who had contracted hepatitis and required blood to be tested for the Au protein. Since the early 1970s the American Association of Blood Banks has required all donor blood to be Au-tested.

Eventually the Au protein was found to be a protein on the outer surface of the HBV virus. Fifteen years after Au was discovered, the hepatitis B virus was seen under an electron microscope. But it wasn't until 1986 that scientists were able to grow the virus in a test tube.

Tracking down other hepatitis viruses - the C file

The hepatitis A virus that was present in Dr. Krugman's MS-I sample was found in 1975 by Drs. Stephen Feinstone, Robert Purcell, and Albert Kapikian at the NIH (National Institute of Health). Then they were able to devise a blood test to detect it. Since blood from donors was already being tested for hepatitis B virus and some people were still developing hepatitis after transfusions, the researchers thought these people must be getting hepatitis A.

They took their blood test to Dr. Harvey Alter, who had been studying the blood of surgery patients. To their surprise, none of the patients who had developed hepatitis after transfusions were infected with hepatitis A. The researchers were unable to identify the cause, which they suspected was another virus, so they named the illness *nonA-nonB* hepatitis.

Research in 1978 showed that nonA-nonB hepatitis could be passed to a chimpanzee through innoculation with blood from people experiencing the condition. Although the contaminating agent (now know as HCV) could not be identified, through a process of filtration, it was shown to be around 50nm in size (50 billioniths of a meter).

With conventional research at a dead-end, several groups turned to molecular technology but even this route was fraught with uncertainty.

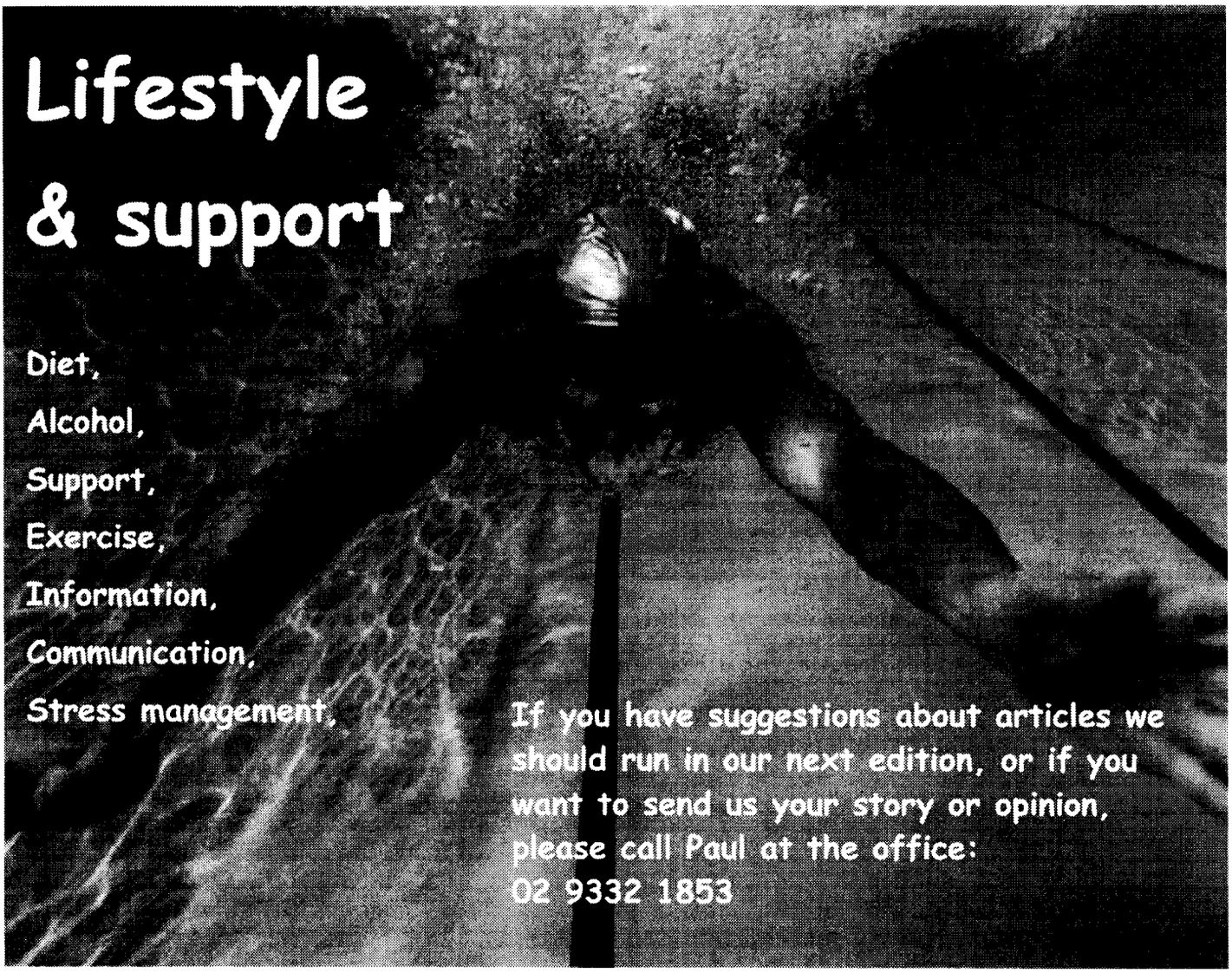
For some time, microbiological researchers tried in vain to identify the agent causing nonA-nonB; understandable considering the commercial prize for success in developing a test for use worldwide in blood screening tests.

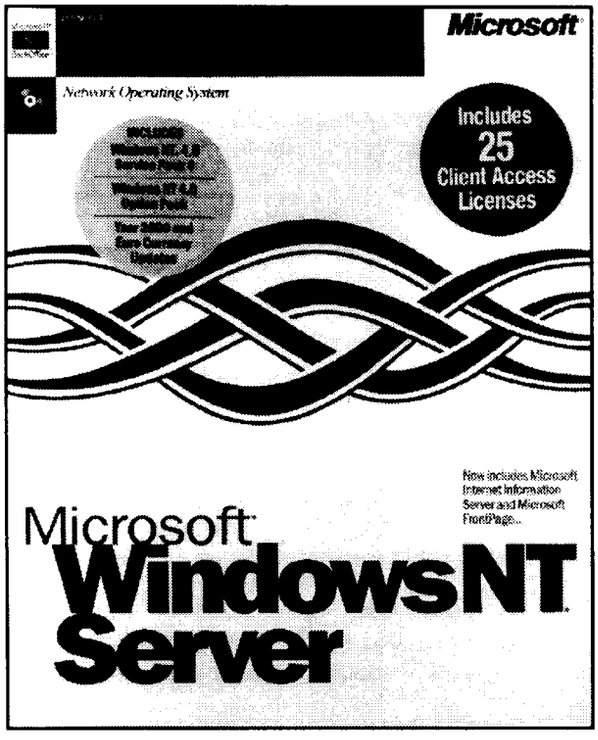
After genetically testing over a million samples, in 1987 Michael Houghton and colleagues at Chiron Corporation in California identified the virus that seemed to be causing most of the cases of nonA-nonB hepatitis. They named it hepatitis C virus, or HCV.

Chiron went on to patent their discovery and develop the first HCV antibody test - called the ELISA 1.

- This is our third and final excerpt of an abridged 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.

next edition



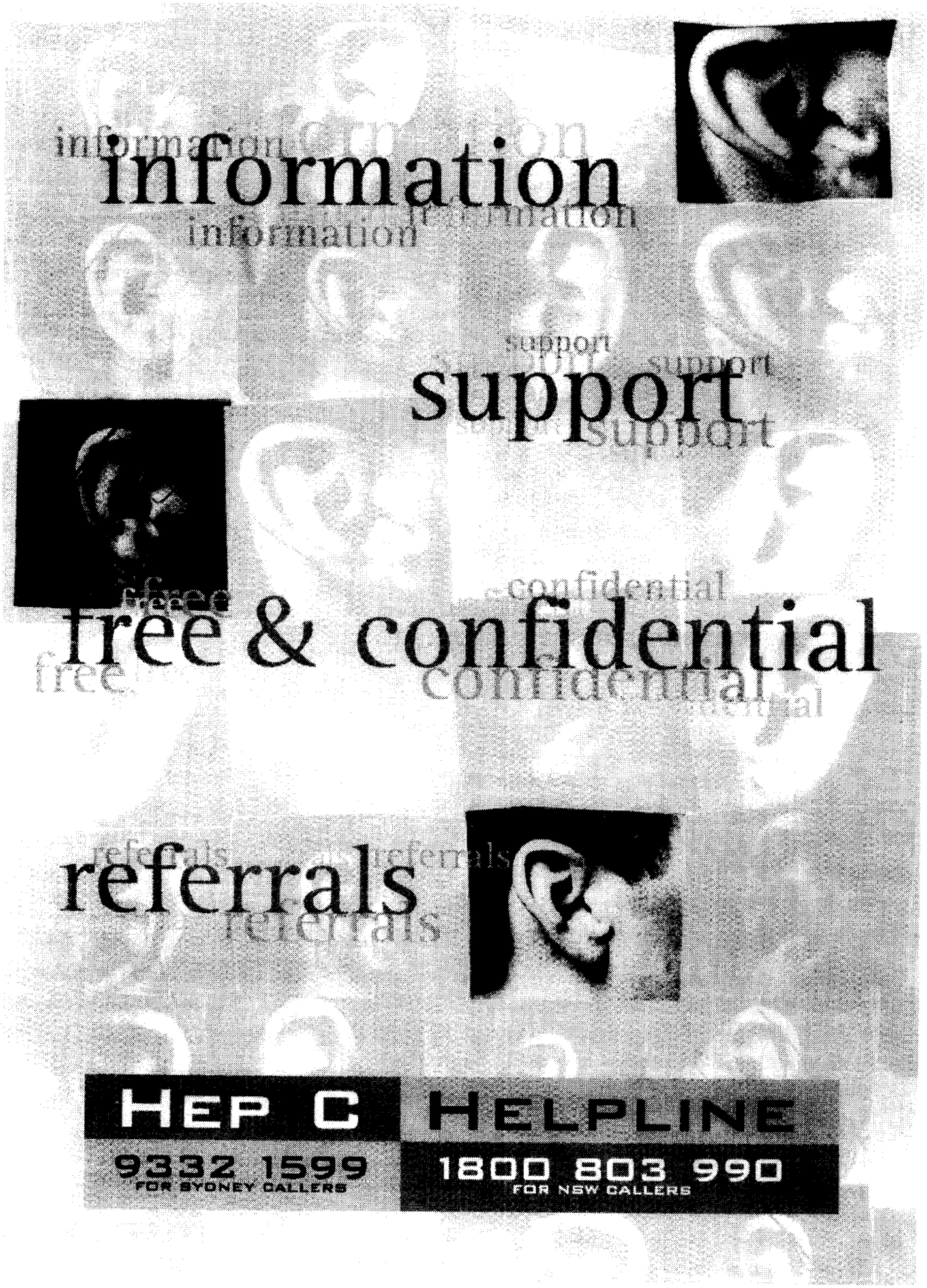


Thanks, Microsoft!

Our thanks go to *Microsoft Australia* who have been able to step in and offer direct assistance within the HCV response here in NSW.

Their generous support - through the donation of various software products - enables the expansion of our computor network and has been warmly welcomed by Council staff and management.

preview of new Helpline poster



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, 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. 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. Group 2: interferon @ 6mu daily for 1 mth, then 3mu 3x weekly for > 1 year. Group 3: interferon @ 3mu 3x weekly for > 1 year.	**(Genotypes 1 or 4)** Group 1: interferon @ 5mu daily for 8 wks, then 3mu 3x wkly for 44 weeks; plus ribavirin, daily for 52 wks. Group 2: interferon @ 3mu 3x wkly for 52 wks; plus ribavirin, daily for 52 wks. **(Genotypes 2 or 3)** Group 1: interferon @ 3mu daily for 4 wks, then 3mu 3x wkly for 20 wks; plus ribavirin, daily for 24 wks. 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. GP visits and health status surveys at 0,1,3,6,9 months. LFTs at 0,1,3,6,9 months. PCR genotyping at beginning of trial. PCR viral detection and viral load tests at beginning and at 24 wks. Group 1: CH100 taken 3x daily for 24 wks. 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 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, Previous treatment, Injecting drugs (oral methadone OK), Hep B coinfection.	Having cirrhosis, Previous treatment, Injecting drugs (oral methadone OK), Hep B coinfection, Falling pregnant (women), Conceiving a child (men). 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. 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? **(ph contacts)**	Enrolments have closed and Aushep 6 is now in progress.	No, enrolments are now closed.	Enrolment will be open soon. Most of the barriers have been overcome but final approval has not yet been received. 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: Nikki Keefe 02 6620 7518 (Thurs), Tim Sladden 02 6620 7509 (other days, Mon-Fri).

INject YOurSelF DON'T 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 Hep C Helpline 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.*

Researched?

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 some positive benefits and few side-effects (see edition 15.)

Want more information?

For general information about complementary therapies, phone the NSW Hep C Helpline (9332 1599 for Sydney callers or 1800 803 990 for NSW callers).

Additionally, contact any of the following organisations:

Australian Acupuncture Association	1800 025 334
Australian Homoeopathic 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
Homoeopathic 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 Helpline

For confidential and anonymous information and emotional support you can phone the NSW Hep C Helpline:

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
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 Hep C Helpline.

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, including family counselling.

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, contact *TRAIDS* (above), 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 Hep C Helpline* (see above, top left).

Stop Press

Speak Spanish?

A website about hepatitis C for Spanish speakers has recently been developed. It has received good reviews and can be found at:

http://www.healthfinder.gov/justforyou/espanol/default.htm

"Dr Akagi"

This new Japanese film - reported to be a comedy about hepatitis - was screened recently on the US 'art house' circuit. American heppers saw it and gave good reviews.

Lu reported it was "terrific". She saw it as a "tragicomedy about a doctor obsessed with finding a cure for the hepatitis he sees all around his village during the last days of World War II.

CDC hep C recommendations

The latest Centres for Disease Control recommendations for Prevention & Control of HCV are available in PDF format to download from:

http://www.pacificcoast.net/~hepcvic/hepcvic~1.htm

Sad news from NZ

Stephen Blake of the NZ Hepatitis C Support Group died on 25 April 1999. Our thoughts are with Stephen's family - and all those across the Tasman affected by HCV.

Stephen was such a key player in the NZ community response to hepatitis C and will be greatly missed.

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

Ed 24 - alternative therapies / fatigue / pegasys interferon trial

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

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

Hep C Helpline - Posters and calling card (bulk copies available 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.

Cardholder's signature

MasterCard	Visa	Bankcard

Card type (please circle)

month		year	19

Card number

Expiry date

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.

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