

The Hep C Review

Spring / Summer Edition December 1998

Edition 23

HEPATITIS C REPORT CALLS FOR URGENT GOVERNMENT ACTION

The NSW Parliamentary Standing Committee on Social Issues report, *Hepatitis C: The Neglected Epidemic*, was tabled in State Parliament on 11 November and listed for formal debate in April, 1999.

Committee chair, Jan Burnswoods, MLC, said that the evidence taken and submissions received from people with hepatitis C portrayed the stark realities of the disease: the overwhelming and debilitating fatigue; the fear of transmitting the virus to partners, children and grandchildren; feeling of uncertainty about the future; and failing health.

The Committee found hepatitis C to be a disease that has been largely neglected by decision makers, health planners, the media, healthcare workers and the community in general. It could find no over-arching policy to guide and direct the control, treatment and prevention of hepatitis C in NSW.

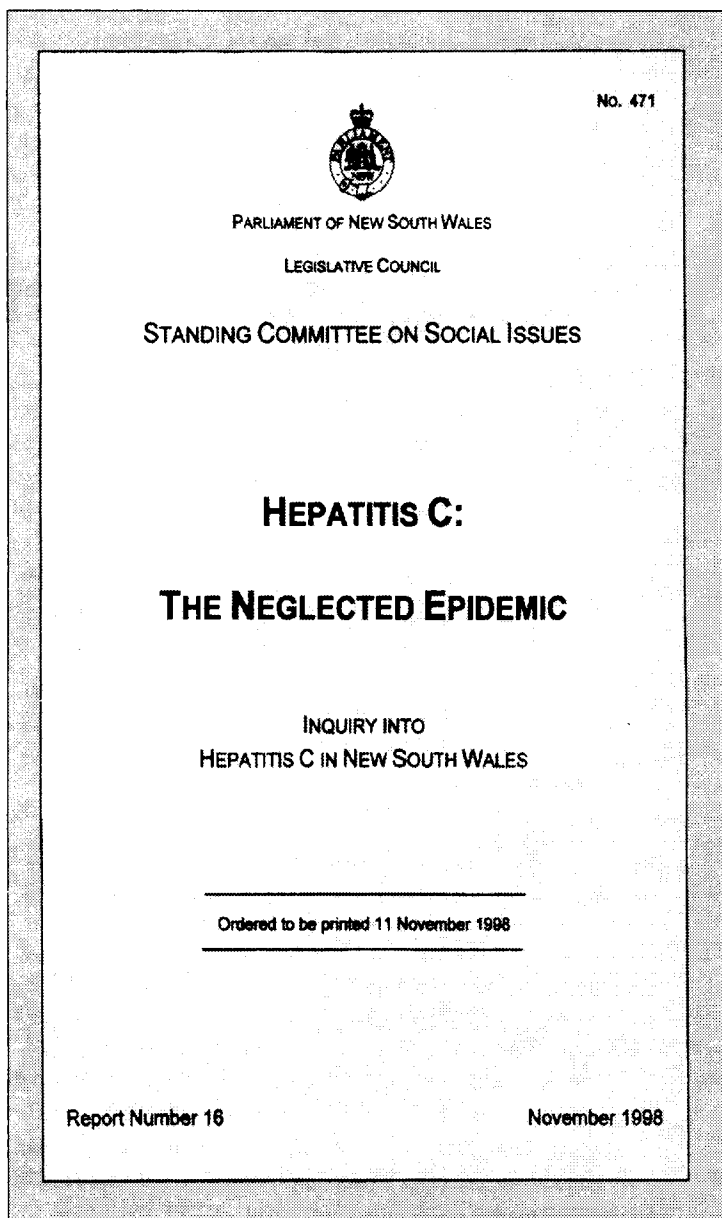
Hepatitis C: The Neglected Epidemic represents the most up to date and comprehensive attempt to define and address the hepatitis C epidemic in NSW. It should have far reaching positive consequences for NSW and the rest of Australia.

The report's key conclusions relate to: strategic planning and policy development (including better clinical healthcare services); prevention of HCV transmission; prisons and HCV; further hepatitis C research; raising community awareness and redressing discrimination.

Following an introduction, the report covers: hepatitis C's profile; groups at risk of infection, social and economic impact; hepatitis C strategic planning and policy; diagnostic issues; treatment and management of hepatitis C; complementary therapies; treatment and management within prisons; supporting people with hepatitis C; preventing transmission of HCV; and advocacy for people with HCV.

Aiming to explain the hepatitis C situation and provide context for its many recommendations, the report contains bibliography, numerous appendices and more than 30 tables and figures.

For more information, see pages 3 & 27.



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info update:
time for action

an overseas hepatitis C update
treatment "response" & trials update, genotypes
Hepatitis C: The Neglected Epidemic

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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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Hepatitis C: The Neglected Epidemic

By Stuart Loveday

Hepatitis C: The Neglected Epidemic is the hard hitting and honest title given to the report from the Inquiry into Hepatitis C in NSW tabled in Parliament on 11 November. This unique, landmark report of the Standing Committee on Social Issues of the NSW Legislative Council places hepatitis C firmly at the forefront of evidenced social need in NSW.

Recommendations arising from previous inquiries by this eminent upper house committee into social issues affecting the lives of people in NSW have a good track record of effective implementation.

The Hepatitis C Council, together with our members, many friends and contacts, welcome this report. We shall be using it as a the key tool to push for major change in the ways NSW Health and other government departments approach the dual requirements of HCV prevention and vastly improved care, support and treatment for those affected. We welcome the report's firm commitment to Australia's harm minimisation principles.

The real challenge now for the NSW government is to provide sufficient and sustained funding to meet this public health crisis head on, and to provide the necessary commitment and resources to carry out Parliament's recommendations.

Why is this report of such major significance? Some may suggest that the report is just another wish list - just another list of recommendations that will gather dust while infections continue across Australia at the rate of 30 per day; while the estimated 90,000 people in NSW living with hepatitis C in NSW suffer inadequate support and treatment, stigmatisation and varying levels of discrimination and vilification. For different reasons, our Government should take real action this time.

Firstly, what we have now is a high level, political document that builds on the momentum of years of accumulated evidence - it's time for action.

Secondly, we have unanimous agreement in the Standing Committee on all 131 recommendations that call for concerted and funded action by Government. With full agreement from all political parties represented on the Committee - Labor, Liberal, National and Australian Democrats - we stand to gain further momentum and support from debate in Parliament in early 1999.

Thirdly, we have a clear, top level indictment of the inaction in all HCV matters by successive governments, identified and acknowledged by representatives of those governments themselves.

Fourth, we have a clear, powerfully argued and extremely well evidenced set of recommendations.

Finally, quite simply, we have the position that if governments do not take heed and provide resourcing and direction now, they are ensuring a massive additional and totally unnecessary health cost, social cost, and welfare cost burden that will be borne by voting citizens of Australia as a whole.

Step number one in the NSW government's strategy must be to increase public and politicians' awareness of hepatitis C. Still, in November 1998, we have Federal Government media releases sowing confusion by referring to hepatitis C as "the most commonly notified HIV-related disease in 1997". Channel 10 News picked this up and said the people most at risk of HCV infection were "young people who practise unsafe sex". Both of these statements are wrong.

"The real challenge now for the NSW government is to provide sufficient and sustained funding to meet this public health crisis head on, and to provide the necessary commitment and resources .."

An awareness campaign will not only inform the public and give everyone the real facts, but will demonstrate to budget holders that to spend a bit of money now, they can save a whole lot more money later on. By giving people the tools to help manage their health better themselves, they will create less of a demand on already scarce health resources. And by reducing discrimination against people with hepatitis C, society as a whole would be better off. Simple, you'd think.

We welcome the report *Hepatitis C: The Neglected Epidemic*, and congratulate the Standing Committee on Social Issues on its swift and timely production.

Now there is no excuse for continuing to ignore the epidemic.

- Stuart Loveday is Executive Officer of the Hepatitis C Council of NSW.

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HIV or HCV

I thought I would tell you a bit about what has happened to me. Finding out I had hepatitis C hit me like a bomb.

People that I thought were friends suddenly didn't want to know me. They thought you could catch it by having a cup of tea at their home.

Things are starting to get a bit better now, but I don't tell anyone that I have HCV anymore. What I feel has made this so hard, is that in my town the population is only 1200 people.

I have been called a disease-ridden whore even though I've been with the same partner for 10 years and have never played up.

My partner has an HCV blood test every year and has been clear from day one. I'm probably worried about him giving something to me that could affect my liver! But I'm more worried about the misinformation other people have about hepatitis C.

I did a first aid course and the teacher (an Ambulance Officer) started the course with a hand shake to one of the students and then said "I have just been to the toilet and didn't wash my hands. You now have hepatitis C."

By this time, I had the biggest lump in my throat (just like I'm getting now). Then he said one of his friends had died from hepatitis C after only having it for 5 years.

I stood up and said that I had hepatitis C. He looked at me and said I must be a healthy one because he didn't know of me.

One of the students stood up and said he wasn't staying because he might catch it from breathing the same air. No one would touch the CPR dummy if I touched it before them. The whole thing was horrible and I would never want to go through it again.

A lot of people have said to me that they think it is the same as AIDS because the letters are almost the same - HIV and HCV. So they think you can catch it the same ways.

I think the public needs to be more aware so these sorts of things stop happening.

I've said enough, so bye for now

Liz



I'm not alone

Thanks for the recent information pack. I was not going to fill in the membership form but then I read The Hep C Review and changed my mind.

Reading other people's stories in the 'my story' sections has helped me a great deal.

I had just about forgotten there were thousands of people HCV positive. I felt alone and isolated until I read about other people's experiences with HCV.

I have regained some strength from being reminded that I'm not alone.

Thank God the magazine was included in the info package. I was going crazy reading about all the facts and research. The human side is so important.

Regards, Helen



Aussie rules

I'm really terrified about asking this question and don't know how to go about getting information and assistance. I hope this letter will arouse some interest and somehow, I will get some answers.

My fiancé is HCV+ and is planning to undergo interferon treatment this month - but overseas.

I'm an Australian citizen and don't know how I would cope if I had to go and live overseas. But my fiancée is not a citizen and I do not know if the Department of Immigration will permit him to stay in Australia. I don't know what the policies are and I'm too afraid to ask in case I later decide to sponsor him and I face discrimination.

I highly doubt that he will pass hep C on to anyone else or that he will be a burden on the healthcare system as he is having his therapy overseas, and he is in relatively good health.

He showed no signs of illness and only discovered his HCV status after a routine blood test that revealed elevated ALT. His biopsy has shown no damage, and doctors say that he is quite capable of work and a normal healthy life.

I'd really prefer to stay here in Australia but I love this man very much and am in a very difficult position right now. I would hate to have to move overseas because I love someone who may not be granted residency due to HCV.

I plan to get information from the Dept of Immigration but don't dare reveal too much at this point. But how do I answer the questions and what do I reveal. What does the law require? What are my rights?

I'm sure there are people who would say it is wrong to bring more people into the country with HCV but we didn't know he had HCV when we met. Nor did I expect to fall in love with someone whilst overseas.

At this point I hope everything goes all right with the interferon treatment. Later we will see what we can do about being together again. I would appreciate any information regarding HCV immigration policy.

Name withheld

[Yes, the Department of Immigration will ask people with HCV who apply for residency to show that they won't place any significant future demand on our healthcare or social security systems. It seems that in proving this, individuals are relying on their doctor's and specialist's opinions, and their LFT and biopsy results .. Ed]



herbal help sought

I estimate I contracted hep C in 1969 through sharing with American servicemen on R&R leave. Symptoms of chronic fatigue, full body ache, abdominal pain, etc. have been developing in me for all that time, getting worse and worse.

I've lost jobs because I would be sick for days after a drinking session. Totally collapsed in bed for days and not knowing why. I was told I had nonA-nonB hepatitis in 1984.

In June, I went on interferon which left me impotent and brought out some chronic mental health agitation for which I am now seeing a psych.

I've just had my liver biopsy no. 2 in September. I'm not sure what the results meant but am going to be interviewed to accepting the high dose interferon program.

I've been thinking of using herbal stuff and am wondering is there anything the Council can provide? I seem to be deteriorating at the moment. Any news of help would be gratefully latched onto.

Thanks, Rick

[Rick. Thanks for your letter. We provide information about herbal medicines and other complementary therapies in several of our publications: Hepatitis C What You Need to Know (pg. 11) and on page 37 of each edition of The Hep C Review. Edition 10 focused on complementary therapies so you'll also find specific articles there. Our next magazine, Edition 24, will have a general focus on complementary therapies ... Ed]



Ciao from Italy

Friends in Australia, I am connected with the HEPV-L internet email list and noted some of your recent messages. We are a very little group of people in Italy having started since one week a mailing list.

If you have some Italian people there in Australia who would like to exchange some email in Italian language, please spread our address to them.

To subscribe to our list people have to go to our web site:

<http://epac.listbot.com>

Thank you.

Ivan from Italy
(gardini@idea.it)



a quilt community

Thanks Hep C Council NSW for writing with your interest in the US Hep C Quilt. Our US Hepatitis C Quilt symbolises the spirit of Americans who are coming together to raise awareness around hepatitis C and foster our emerging American hep C community.

The product of individual effort, the quilt travels the US and is featured in political marches, support group meetings, public presentations and media events.

Recent travels include the protest march on Washington DC; several support meetings in Orange County, California; a booth display in Portland, Oregon; Jeanie's Hepfest in Massachusetts; the protest march on Salem, Oregon; the Stidham, Oklahoma Hepfest; the Buchanan Hepfest in Brookland Park, Minnesota; and the Angels game in San Francisco, California.

letters

The Quilt is formed of individual squares and constantly growing. Sometimes featuring personal messages, squares often feature people's handprints.

It symbolises the growing community mobilisation within America for a better national response to hepatitis C - one hinging around community education, improved treatment facilities and more effective prevention initiatives. It grows steadily as more and more people send in panels. Many have been sent in over the last few months, our photo provided will probably be out of date.

We'd like to thank you for promoting the quilt in your Australian magazine and would welcome anyone wanting to send across a panel. The message our quilt promotes is certainly universal and your contributions would add much to our project. Finished panels should measure 12" x 12". Any colour is fine, especially red or yellow. We suggest cotton cloth as the panel base as this is easier for us to work with.

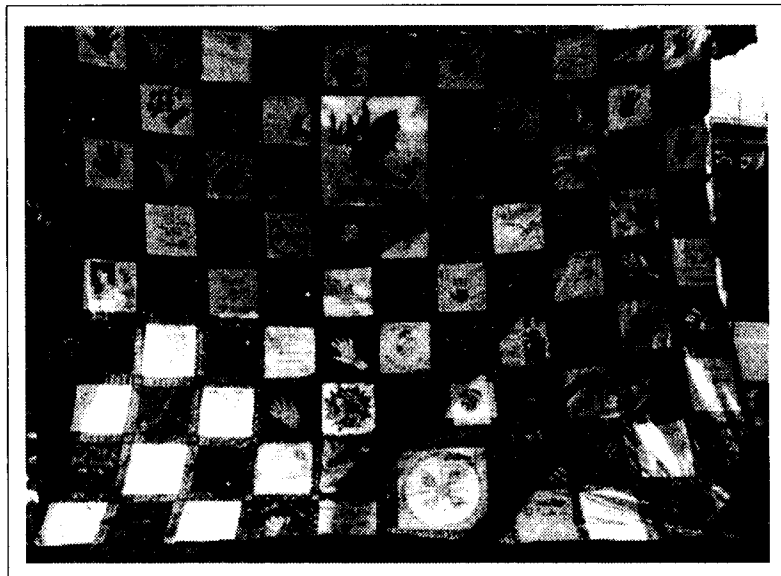
Many people trace their hand using the opposing colour (red v. yellow) and put their name and date when they contracted HCV. Other people are being creative and developing their own designs.

Quilt panels should be sent to
Mrs Marie Stern
4918 W, 135th St
Hawthorne, Calif. 90250

Thanks again so much for your interest,

Marie

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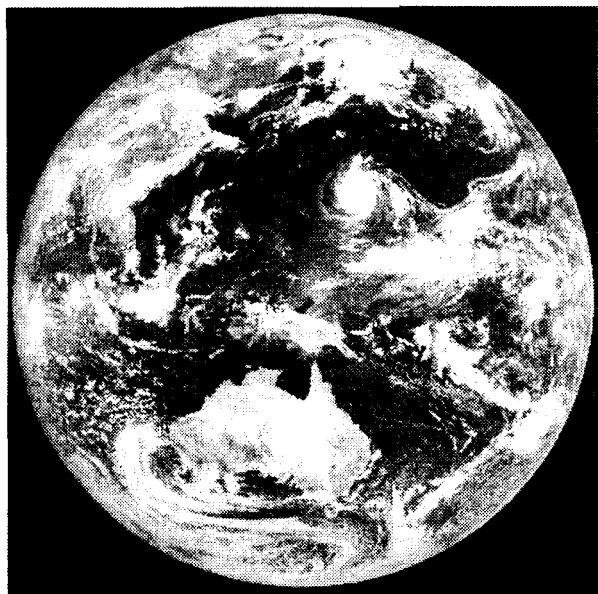
Within this edition of *The Hep C Review*, we make repeated reference to the internet email membership list, HEPV-L. In joining the list, you can send a message to thousands of hep C people world-wide by posting it once to a central computer at a US university. Depending on your settings, you can also receive all or just some of everyone else's email messages.

To find out more about HEPV-L, send a simple email message to:

LISTSERV@MAELSTROM.STJOHNS.EDU

Within the addressee and subject boxes, just hit your space bar a couple of times so as not to enter anything. Within the actual email message box, just type in HELP. Then send it off.





What's been happening overseas with HCV?

We planned that this edition of *The Hep C Review* would provide an overseas overview of what's been happening with HCV - news on treatments, political action, support services and research, etc.

If ever there was an edition 'focus' we would fail to adequately cover, perhaps this is the one. Yes, we have accessed some overseas news, but it has been difficult.

There is a far greater likelihood of finding information from the United States, Canada and the United Kingdom. Try to find out about other countries - especially non-English speaking - and things become difficult.

Consequently, in this edition we can only provide a very limited outline of what is happening overseas.

Please remember that some of the HCV information contained in our feature articles will not be relevant to us here in Australia. Although much of this information may be interesting to us all, please don't take it as the gospel truth.

Without suggesting that Australia should rest on its laurels, it is heartening that in comparison to many overseas countries, we do enjoy a better hepatitis C response. This is qualified, although, by the fact that we still have so much more to achieve - as highlighted within the NSW Parliamentary report: *Hepatitis C: The Neglected Epidemic*.



Separate strategies

Within development of a fourth National HIV/AIDS Strategy, strong calls have been made to separate the strategy and funding for hepatitis C (as reported in the Sydney Star Observer).

The 1st and 2nd HIV/AIDS strategies related solely to HIV/AIDS but the most recent (1996) was broadened to include hepatitis C - under the guise of a 'related communicable disease'.

It is believed that the political merging of hepatitis C and HIV under the banner of 'HIV & Related Diseases' has led to unnecessary confusion within the healthcare and welfare fields, and within the eyes of the general public.

Aiming to lessen current and future competition between HIV and HCV for limited funding resources, calls have been made for separate federal funding sources.

Coincidentally, concrete moves have already been undertaken in NSW to develop a revised dedicated hepatitis C strategy. Although, the *NSW Hepatitis C Strategic Plan* is currently in its initial draft stages, it will soon be released for public comment. Once completed, it will replace the existing *Report of the NSW Hepatitis C Taskforce* (1995) as our State's key HCV strategic plan.

This valuable initiative is expected to coincide with a current review of Australia's *Hepatitis C National Action Plan* and the NSW Parliamentary Report into Hepatitis C (see front cover).

USA lookback notification

The US Food and Drug Administration has released guidelines requiring hospitals and blood centres to inform transfusion recipients who received blood that might be infected with the hepatitis C virus.

Blood centres should start notifying hospitals about potentially contaminated blood "as soon as feasible" and within six months at most. For current patients, hospitals have 12 weeks to notify those at risk for hepatitis C.

For past patients-going back to 1988-hospitals have one year to complete notification after receiving information from a blood supplier.

The guidance gives hospitals the option of notifying patients directly or through their physicians.

Modern Healthcare, Sept. 28, 1998

- Taken from the internet email list: HEPV-L

[The NSW Blood Bank instigated a statewide lookback program back in 1996 - see Ed 14, page 5.]

Education for people who use drugs illicitly

By Jude Byrne

The Australian Intravenous League's National Education/Prevention Program for people who use drugs illicitly (PWUDI) is six months into its activities. We have been funded for a two year program of activities in much the same manner as the Australian Hepatitis Council.

The significance of funding these programs should not be overlooked. It signals a change in the attitude of Government toward hepatitis C in the provision of education, treatment and support. It helps bring the infected/affected community into the partnership of government and service providers. This can only help ensure the response to Australia's HCV epidemic is mindful of the needs of people living with hepatitis C.

The AIVL Program aims are to:

- develop and implement a National HCV Strategy targeting PWUDI
- encourage health maintenance and monitoring amongst PWUDI
- encourage provision of and access to quality support treatment and care services to PWUDI
- encourage an evidence-based approach to the development of an education and prevention strategy.
- ensure a coherent and effective national response to HCV through training and professional development for agencies working with at risk groups.

As anyone who has undertaken a national education campaign for a very diverse community will know, this is an extremely challenging process. Fortunately AIVL has the enthusiastic support and involvement of the state and territory based user groups. These groups will ensure the program is focused appropriately and the resources are distributed to the targeted communities. It also allows for each region to have its own imprint and issues addressed within the resources and other activities.

Education or information for PWUDI about hepatitis C health maintenance and monitoring will not be of much value until these clients feel able to

access services and be treated in an equitable non-judgmental manner. To address these issues a training workshop will be developed with the AHC who have received funding to develop and implement the workshop with input from the AIVL program. Hopefully this workshop will help address some of the problems and barriers that service providers face when dealing with PWUDI and their specific issues in relation to hepatitis C.

The program will publish a quarterly newsletter titled *Hepatitis See* providing information on relevant issues. *Hepatitis See* will provide a national forum for extending debate and discussion on those issues. We welcome any information or ideas for publication that will enhance the effectiveness or reach of the program. *Hepatitis See* will be distributed soon and if anyone would like more information or would like to receive quarterly publications please contact us on:

Ph 02- 62817851

Fax 02-62817853

Email jude@netinfo.com.au

- Jude Byrne is Coordinator of the AIVL National Education/Prevention Program.

ACT lookback program launched

By Jo Schell

The ACT Hepatitis C Lookback Program commenced on the 18th of August 1998 with an announcement by the ACT Minister for Health & Community Care, Michael Moore.

Lookback aims to identify recipients of blood products potentially infected with HCV and to offer them counselling, risk management advice and medical care. This process occurs in two ways:

Donor-triggered lookback:

This takes place when someone who has not donated blood since 1990 (when screening began) is found to be HCV positive. As it is not possible to determine when the donor became HCV positive, the Red Cross provides an extensive list of the donor's blood donations. These are then traced to recipients via a complicated process of record matching at the hospitals where the blood was used.

ACT Health and Community Care are in the process of commissioning a data retrieval system which will streamline the donor-triggered lookback process.

Recipient-triggered lookback:

This occurs when a person is diagnosed with HCV and identifies blood transfusion as a risk factor. Any blood donations that the person received need to then be matched back to the original blood donors and each donor is then tested for HCV to determine which blood donation, if any, was HCV contaminated.

This process is also painstaking as some people have received over 30 blood donations and each of those 30 donors must be contacted for follow up.

There are many 'wheels turning' with the ACT Lookback process at the moment. Counsellors have been trained to provide appropriate care for those with fears about HCV and have staffed a Crisis Line from 9am to 9pm that can deal with urgent concerns.

For more information, people can phone the ACT Hepatitis C Lookback Program Coordinator, Jo Schell, on 02 6205 1943.

GPs have been informed of the potential for an increase in people seeking HCV antibody testing and are equipped to deal with people's queries.

HCV notifications made by GPs to the department are being investigated as are those made by the Red Cross.

The department is currently developing a financial assistance package available to people who received HCV contaminated blood products in the period between 1985 and 1990.

- abridged from an article by Jo Schell, ACT Department of Health & Community Care, taken from ACT Hep C News (Vol 1 Issue 1), published by the ACT Hepatitis C Council.

Painkillers may affect liver in hep people

People with hepatitis C may develop elevated levels of liver enzymes, a sign of potential liver damage, if they take ibuprofen, a common nonsteroidal anti-inflammatory drug (NSAID), according to a report in *The American Journal of Gastroenterology*.

Researchers at Pennsylvania State University in Hershey believe that, based on this report, people with hepatitis C should avoid NSAIDs when possible.

The report, based on three case studies, describes patients with chronic hepatitis C infection who were found to have high levels of liver enzymes (transaminases) after taking a course of ibuprofen. Liver enzyme levels returned to normal within 3 months of discontinuing the pills.

The cases support the use of acetaminophen over NSAIDs, Drs. Thomas Riley and Jill Smith stated in their report.

If NSAIDs are deemed necessary for these people, "careful monitoring of the liver function tests should take place with monthly testing (at least) for the first 3 months of use and then every 3 months thereafter," they recommend.

According to the researchers, NSAIDs such as ibuprofen and aspirin are a well known cause of liver dysfunction.

They stated that further study is needed of a large group of people with hepatitis C to determine how often NSAID problems occur and to develop the optimum approach to NSAID use in HCV+ people who have to use the drugs.

According to the report, there are about 4 million cases of hepatitis C in the United States and NSAIDs are often used to address symptoms.

The original research paper was published in *The American Journal of Gastroenterology* 1998;93:1563-1565.

- Abridged from a news release from HepNet, 24/9/98

[The above research is based on only 3 cases out of what would be countless NSAID use world-wide. Calling for more research that will help confirm whether there is a direct association between NSAIDs and liver damage, and if so, how often it occurs, the above research doesn't suggest that people with hepatitis C who use NSAIDs are going to experience problems. If you are concerned, speak to your doctor or pharmacist. We'll pass on any further news as it comes to hand. Ed]

PCR correction

On page one of Edition 22 we congratulated the Commonwealth Government on the recent initiative that, to a certain extent, makes PCR testing more widely available to people with HCV.

We incorrectly stated, though, that one of the four access criteria was:

For people who have experienced a risk exposure (eg. needlestick injury) and want to confirm during the window period whether they have contracted HCV.

This is not the case. This fourth access criteria point should state that, in part, PCR tests are available:

To detect acute hepatitis C, prior to seroconversion, in those people who have signs of acute hepatitis yet other causes have been excluded (eg. hep A or hep B).

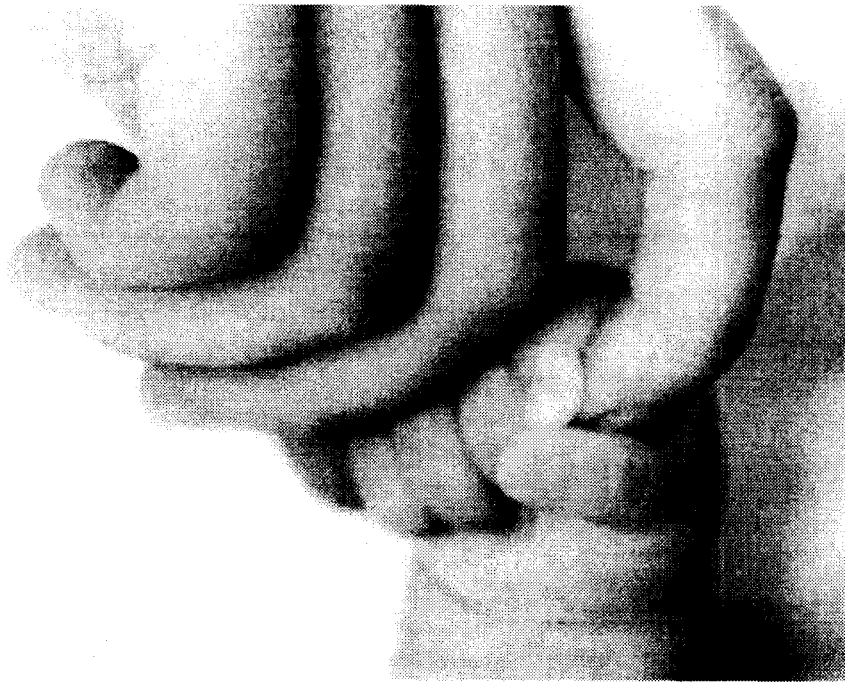
PCR testing is made available in these cases where this information is considered necessary for the clinical management of the person's hepatitis.

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Wanting to know, but not wanting to know

For the last three years I've been on a quest for information about hepatitis C. Reading as much as I could, and trying to make sense of the jargon. Hoping to find some new piece to the puzzle, so there would be almost some sense of security in that knowledge for me.

But, there was one important piece of information right at my finger tips that I wasn't ready to learn.



There was a chance that I had passed this virus on to my daughter, and even though I would wake at night thinking about it, I would try to put it out of my mind. I'd tell myself things like I didn't know I had this virus when I was pregnant, and if I did, I would have wanted her anyway. Or that there was only a very small risk I would have infected her, and the chances are well in our favour that she is healthy.

I still had an uneasy feeling though.

I remembered how the paediatrician had voiced concern over her yellowish tone before we left the hospital, and reminded me to bring her back for a guthrie test (for jaundice).

I often found myself looking at the dark circles around her eyes and hoping her liver was functioning properly.

I wondered how I could live with the guilt if I had given this to her. How could I explain it to her grandparents. How could I ever tell her.

My family don't even know I have HCV. There would be so many questions I wouldn't want to answer about my life.

I decided to put off having her tested until I was sure I could cope with whatever repercussions the results brought.

Three years went by, and I still didn't think I was ready, until one morning my daughter complained of pain in her upper right abdomen. I made an appointment for her later that day.

I'd mentioned to her in the past that the doctor can use blood tests to see how healthy I am, and one day she could have her health checked too, so it came as no surprise to her when I suggested it. I told her the doctor would use a special cream that would numb her arm and she would barely feel a thing. She was still a bit worried, but the thought of take-away afterwards helped.

Our doctor was very reassuring, he said all the right things, but it really made no difference to me at this stage.

This was the test that had caused me so much anxiety, fear and guilt. I don't think he understood how I had felt for the last three years, wanting to know, but not wanting to know. "Call me in three days" he said as I left.

I tried to occupy myself with anything I could think of, anything to distract me from the bad news I was expecting. I felt like crying every time I looked at her, the ache in my heart was unbearable.

On the third day I waited on hold with my fingers crossed for the doctor to find her results. "Ah yes, it's negative," he said.

I asked him to repeat it again, I could hardly believe it. When I put the phone down I laughed and cried with relief.

from Jean

- Taken from *Hep C Community News*, Issue 6, Sept. 1998, published by the Hepatitis C Council of SA.

HCV genotypes

It is much easier to talk of the hepatitis C virus as if it is a single organism but in fact it is a range of viruses, similar enough to be called hepatitis C virus, yet different enough to be classified into subgroups.

Viruses are microscopic and no person could ever see them with the naked eye. Indeed, HCV is so small that there's been no confirmed actual sighting of it using any type of microscope yet developed (see Ed 17, p1).

Consequently, a better way to understand the terms HCV 'genotypes' and 'subtypes' is to compare them to things that we can more readily relate to.

Genotypes

The group of birds we call 'raptors' (birds of prey) have evolved into different main types. Imagining raptors as being hepatitis C viruses, you could take one major raptor type, such as eagles, and imagine these as being one of HCV's main types (genotypes).

Subtypes

But eagles as a group are made up of different subtypes such as the American Bald Eagle and Australia's Wedge Tailed Eagle and Sea Eagle. You could imagine each of these as being one of the HCV subtypes that make up an HCV genotype.

Quasispecies

Within each of above particular types of eagles, there are further differences. All Wedge Tailed Eagles, for example, differ from each other in regard to wing span, weight, colour, beak size, etc.

Similarly, within a hepatitis C sub-type, individual viruses differ from each other ever so slightly. Such viral differences are not significant enough to form another sub-type but instead form what's known as quasi-species. It is believed that within an HCV sub-type, several million quasispecies may exist.



Scientists predict that people who have hepatitis C, have billions of actual viruses circulating within their body. Although there may be one or two predominant sub-types, the infection as a whole is not a single entity and is composed of many different quasispecies.

Classifications

Biologists are generally not known for creativity when it comes to naming things - hence hepatitis C virus. The most commonly used classification of hepatitis C virus has HCV divided into the following genotypes (main types):

1, 2, 3, 4, 5, 6, 7, 8, 9, 10 and 11.

As we've highlighted, HCV genotypes can be broken down into subtypes, some of which include:

1a, 1b, 1c	2a, 2b, 2c	3a, 3b
4a, 4b, 4c, 4d, 4e	5a	6a
7a, 7b	8a, 8b	9a
10a	11a	

Genotype patterns

It is believed that the hepatitis C virus has evolved over a period of several thousand years (see Ed 20, p7). This would explain the current general global patterns of genotypes and subtypes:

- 1a - mostly found in Nth & Sth America; also common in Australia
- 1b - mostly found in Europe and Asia.
- 2a - is the most common genotype 2 in Japan and China.
- 2b - is the most common genotype 2 in the US and Nthn Europe.
- 2c - the most common genotype 2 in Wstn and Sthn Europe.
- 3a - highly prevalent here in Australia (40% of cases) and Sth Asia.
- 4a - highly prevalent in Egypt
- 4c - highly prevalent in Central Africa
- 5a - highly prevalent only in Sth Africa
- 6a - restricted to Hong Kong, Macau and Vietnam
- 7a and 7b - common in Thailand
- 8a, 8b & 9a - prevalent in Vietnam
- 10a & 11a - found in Indonesia

It's believed that of the estimated 160,000 Australians with HCV, approx. 35% have subtype '1a', 15% have '1b', 7% have '2', 35% have '3' (mostly being 3a). The remaining people would have other genotypes.

Genotype and treatment

Current scientific belief is that factors such as duration of a person's HCV infection, their HCV viral load, age, grade of liver inflammation or stage of fibrosis may play an important role in determining response to interferon treatment.

Recent studies have suggested that a person's HCV subtype (or subtypes) may influence their possible response to interferon, or interferon-ribavirin combination treatment. World-wide trials are being conducted which will soon shed more light on this belief.

We'll publish any reports as they come to hand.

- Info taken from *Genotypes and Genetic Variation of Hepatitis C Virus* by G. Maertens & L. Stuyver, reviewed by Dr Greg Dore of the National Centre in HIV Epidemiology & Clinical Research.

For further information, see PCR & interferon (Ed 20, page 12) and Prof Geoff Farrell's report *1997's Chicago Conference* (Ed 20, page 10).



US action against Schering-Plough

In June, the U.S. Food & Drug Administration (FDA) approved ribavirin for use with Schering-Plough's interferon, packaged as Rebetron. This 'bundling' practice makes it impossible for doctors and their patients to consider other choices in the type of interferon they use. HAAC emphasised that they will make it their highest priority to fight FDA approval for new uses of the combination therapy in its currently bundled package.

Representatives from Schering Plough Pharmaceuticals met with the Hepatitis C Action & Advocacy Coalition (HAAC) regarding lowering the price, ceasing aggressive marketing tactics, and the unbundling of Rebetron, a combination of Schering's interferon and ribavirin for treatment of hep C.

Schering stated that they would unbundle the ribavirin if it is deemed "clinically necessary". Schering proposed expanded access to ribavirin alone for patient use and doctor initiated research, under special circumstances. However, they were completely unwilling to consider any price reduction.

A resolution authored by Supervisor Leland Yee and passed unanimously by the SF Board of Supervisors on Oct. 13th supported all of HAAC's demands. The resolution strongly urging Schering to revise their business practices was read by Kieran Flaherty from Mark Leno's office and presented to Schering representatives. Schering was given over 700 letters of support for HAAC's Demands from around the country.

Representatives from FDA and Congresswoman Pelosi's (D-CA) office attended the meeting. Also in attendance were aides from the Board of Supervisors' offices of Tom Ammiano, Mark Leno, and Gavin Newsom, as well as various community health advocates.

Schering agreed to other proposals from HAAC including clarifying and revamping their patient assistance program, ceasing aggressive sales tactics with patient groups and working more closely with the HCV patient community.

- Taken from the HEPV-L internet email list. Also see feature article, page 32.

Walkers take to the street to battle friend's disease

By Howard Gregory, The Bergen Record (New Jersey, USA)

It was hot and muggy, but New Milford restaurant owner Domenica Pero and a small group of friends didn't mind walking 10 miles Sunday afternoon to let a friend and others suffering from hepatitis C know that they are not alone.

A couple of dozen people participated in the walk to raise both awareness of this disease and money for Beth Quigley, a 55-year-old mother and grandmother who contracted hepatitis C after an emergency blood transfusion 31 years ago.

Quigley was touched by the effort.

"I am totally overwhelmed by all of the support my friends and family have given me," she said. "What we raise will go toward research and hopefully toward finding a cure."

The walk was co-sponsored by Jukebox Radio 103.1 FM and the Jack Pero Foundation, an organisation Domenica Pero created in honour of her late father to give back to the communities that have been good to her during six years in the restaurant business.



Clinton administration endorses yet nobbles United States needle exchanges

Pero, who scheduled the walk on the fifth anniversary of her father's death, said she had hoped to raise about \$20,000. She had raised about half that amount when the walk started.

Pero originally planned to walk alone, but as the day approached some friends offered to join her. Wearing blue T-shirts that read "1st Annual Jack Pero Walkathon for Hepatitis C Awareness," they headed down Riverview Avenue near Pero's New Bridge Inn toward Quigley's Woodcliff Lake home. They arrived a few hours later.

One walker, Dr. Alisa Robinson, a clinical psychologist, this year created the first support group for hepatitis C sufferers in Bergen County.

Another friend, Diane Cardinali, walked the last five miles of the route. Cardinali, who has lost two friends to the disease, said hepatitis C organisers must make the same political push for their cause as ACT-UP makes for AIDS.

An estimated 4 million Americans suffer from hepatitis C. Each year, 8 to 10 thousand Americans die from it. The number is expected to triple by 2010 and exceed the number of deaths caused by AIDS, according to the Centres for Disease Control and Prevention in Atlanta.

- From the internet email list, HEPV-L



As reported recently in daily papers, in order to prevent ongoing HCV and HIV transmission, the Clinton administration has formally endorsed US needle exchange - but in an alarming display of gutlessness, has refused to allow federal funding of exchanges.

US studies have shown that needle exchange programs reduce transmission of bloodborne viruses - and save lives - without promoting illegal drug use.

Given Clinton's funding approach, exchanges across the US will have to rely on State or local funding in order to have any positive effect on HCV transmission.

Opponents of needle exchange, such as Gerald Solomon, a New York Republican, applaud Clinton's ban on funding. "Supplying drug addicts with needles is counterproductive and sends entirely the wrong message," he said.

Another exchange opponent, Senator John Ashcroft, a Republican from Missouri echoes Solomon's views. He considers any government endorsement of needle exchanges will send a message of accommodation and tolerance toward illegal drugs.

Against this growing conservative resistance, US Health & Human Services representatives insist that needle exchange programs, as part of a comprehensive strategy, do not encourage the use of drugs. They say that carefully designed programs can also be used as a bridge to pull people who inject drugs into using health services.

US Surgeon General David Satcher agrees, saying that, "public endorsement of the principle of needle exchanges is a major step forward" and that this would lead to "more quality programs."

Making it clear that he favoured more needle exchange programs, he put the straightforward case upon which Australia's long-time already existing programs are based: "more prime quality needle exchange programs save more lives."

Additional support has come from the American Medical Association who encourage needle exchange programs and drug treatment as a way to combat the perils of unchecked bloodborne viral illnesses.

- From the internet email list, HEPV-L



Secret talks on compensation for hep C Canadians fuel suspicion

By Dennis Bueckert, The Canadian Press.

Six months after health ministers agreed on a \$1.1 billion compensation package for people who contracted HCV medically, those affected have yet to see a cent and frustrations are rising.

Lawyers are conducting the negotiations in secret and won't say what the hold up is. There are fears the effort could wind up in an impasse.

"I can tell you that discussions are ongoing and nothing's been settled yet," said Toronto lawyer Doug Elliott who is involved in a class action suit on behalf of thousands of people infected through blood transfusions.

Asked how long the talks might go on, Elliott said a class action suit has been scheduled to begin in January 2000 and it will proceed if there is no settlement before that date.

"I think we had all hoped there would be a settlement by now," said Elliott in an interview Wednesday. "We're still trying and we'll keep on trying until it's not working any more."

Last March, the federal and provincial health ministers announced they would offer \$1.1 billion in compensation for people with hepatitis C through tainted blood in the period from 1986 to 1990. But the precise criteria for compensation were left for negotiation, and it now appears there will be different criteria for different categories of compensation.

Critics charge Ottawa has cut a special deal for the most effective critics on the issue, including teen activist Joey Hache and victims represented by the Canadian Haemophilia Society. Hache has a rare blood disease that requires a transfusion every four weeks. Even though he does not know when he was infected, he has been assured by Health Minister Allan Rock he will be eligible for compensation.

People with blood coagulation disorders who acquired HCV through blood products have also

been told they will not have to prove when they were exposed, said Durhane Wong-Rieger of the Canadian Haemophilia Society. They will only have to prove they received blood products in the 1986-90 period. She said her members' concerns are 95% covered and she expects money to start flowing soon.

Other categories of people will have to prove they were infected during the window period, and providing such proof could be difficult since hospital records are far from complete. Deciding on criteria for proof is one of the issues under negotiation, said Elliott.

Michele Brill-Edwards of the Alliance for Public Accountability said those with blood disorders are getting privileged treatment because they comprise a relatively small number of those affected by hepatitis C and have an effective lobby.

Mike McCarthy, representing people with blood disorders in the Ontario region, rejected this view, saying it would be impossible for these people to prove when they were infected because they use blood products so often.

McCarthy conceded almost all these people with hepatitis C were infected before 1986, which would put them outside the official window of eligibility.

The government maintains there was no test available to detect hepatitis C in blood before 1986, but critics say a test which could have prevented most infections was available long before 1986.

- Taken from the HEPV-L internet email list.



Joey gets no promises from Canadian Prime Minister

Fifteen-year-old and hepatitis C positive, Joey Hache managed to get a meeting with the Canadian Prime Minister, but he came out empty handed. Hache failed to convince PM Jean Chretien that the government should compensate all people infected with hepatitis C through tainted blood.

"He said he didn't have the money," said Hache following the meeting.

Hache cycled from Halifax to Vancouver during the summer to promote government compensation for all people infected with the liver disease through tainted blood. He collected 50,000 signatures in support of the cause. He did not buy Chretien's claim of insufficient funds.

"We were given hep C, it wasn't our fault that we got it," he said. "We should be compensated."

Last spring, the Canadian federal and provincial health ministers agreed on a \$1.1 billion compensation package to compensate people infected with hepatitis C through blood products between 1986 and 1990.

Hache is one of an estimated 22,000 people whose infection occurred outside that period, and are therefore not eligible for compensation. He suffers from a rare blood disease and requires frequent transfusions. His doctors told him he had hepatitis C in 1991.

In the House of Commons, Chretien noted that Health Minister Allan Rock has proposed a new program to help the victims, and expressed confidence that all provinces will support it. Rock's proposal would provide \$525 million toward treatment for hepatitis C victims, but no monetary compensation for those infected before 1986 or after 1990.

Rock said his plan would ensure victims will have access to medical treatment and drugs.

"We believe that when people in this country are sick they need treatment, not payment."

However the government has provided financial compensation for people infected with HIV through tainted blood, and for some of the people infected with hepatitis C.

Ontario Premier Mike Harris, who has supported the compensation of all people, criticised Rock for simply doing what was legally required.

"There isn't an ounce of compassion, there isn't an ounce of support for the report of the Krever commission that they appointed. I'm disappointed," Harris said.

The government argues it is not liable for infections which occurred before 1986 because there was no test available to detect the virus before then. This is disputed by the victims who note that some countries started screening for the virus before 1986. The issue has to do with the state of scientific knowledge prior to 1986, and when the government should have known that a common blood test could detect the hepatitis virus with approximately 75% reliability.

- Taken from the HEPV-L internet email list.

Canadian Red Cross files petition for bankruptcy

Rebecca Bragg, Toronto Star.

The Red Cross filed a petition for bankruptcy with Ontario Court, general division, yesterday.

After a hearing before Mr. Justice Robert Blair, Red Cross lawyer Joseph Latham described the move as "standard practice" when companies are under court-ordered bankruptcy protection.

The petition provides for a 'later determination' to be made by the court on bankruptcy if Red Cross restructuring plans now under way fail, Latham told The Star.

Faced with \$8 billion in potential damages from hepatitis C tainted blood lawsuits, the Red Cross was granted bankruptcy protection by the court in July.

That means that all lawsuits from prospective creditors must be suspended, unless special permission from the court is granted.

Before the protection period ends next month, the Red Cross hopes to come up with a restructuring plan that will enable the cash-strapped charity to survive in Canada without its blood program.

If the plan fails to meet with the approval of creditors, the Red Cross could be driven into bankruptcy.

- Taken from the HEPV-L internet email list.

Response: when a single word tells a 1000 pictures

One of the major handicaps in discussing hepatitis C is that many people don't understand all the medical terminology.

The uses of terms such as response, relapse, remission and cure evolve rapidly and what was acceptable just a few years ago may not be good usage today. Standards of measuring and testing are also evolving.

Just a few years ago a 'relapser' was a person whose liver enzymes went back up after treatment was stopped. We now know the term 'relapser' has little meaning if the course of treatment was too short, or of an ineffective dose or frequency.

Words as remission and cure also have little or no real meaning unless they are further defined or qualified. Remission, as defined by what? Cure, as measured by what standards?

Thirty years ago, a person was usually considered cured of hepatitis if their jaundice went away. Today that notion would be laughable to hepatologists.

Qualifying hepatitis C terms is not only helpful in terms of talking about the illness, but is absolutely essential for such terms to take on anything but the vaguest and most obscure meaning.

Response

This is probably the most confusing term, because there are so many different kinds of responses, including initial, breakthrough, partial, end-of-treatment, end-of-study, complete and sustained.

Response can also be seen in terms of virological, biochemical or histological.

- * Virological-response is a loss of measurable virus in the blood, often measured by the PCR test.
- * Biochemical-response is the normalisation of liver enzymes (ALT, AST, etc) and other blood tests.
- * Histological-response is an improvement of liver tissue and anatomy, usually measured by liver biopsy. Sometimes the term is used in the same way as biochemical (above) because of the expense of performing biopsies.

Initial Response means the early movement toward normal of a value being checked (biochemical, virological, histological).

Breakthrough-response means a response to therapy seems successful at first but then diminishes while treatment is still continuing. It is usually an indication to stop treatment.

Partial-response is a normalisation of one value (such as ALT) while another remains abnormal (detectable virus via a PCR test).

End of treatment-response is used to indicate the status of response indicators at the end of the period of therapy.

End of study-response usually means the response status 6 months (24 weeks) after completion of a treatment. Plays an important role when researchers evaluate effectiveness of a study drug.

Complete-response refers to a normalisation in all areas of measure, including loss of measurable virus, liver enzymes and sometimes, liver histology as well.

Sustained-response usually refers to a complete response that lasts for at least 6 months after therapy - the one we're all hoping for, folks.

Non-response

is where therapy does not result in improvement in some area of measurement (virology, biochemical, or histologically). The commonly accepted standard now is by virology.

Relapse

implies a response of some kind, and then a return to abnormal values. Relapse can be virological, biochemical, or histological. It usually implies a return of some symptoms, but not always.

Remission

(when currently used in connection with hepatitis C) means loss of all detectable means of finding the disease.

Cure

is a word that most clinicians avoid and people should be suspicious when you see it used. There is no true definition of what constitutes a cure with hepatitis C. It might be used when, after treatment, someone is PCR negative for at least 5 years. But clinicians are not even sure the virus couldn't return even after that time. You may see the word used to describe herbal or other remedies of questionable or clinically unproven value.

Mine is a partial compilation of terms as they are currently used in connection with hepatitis C only. Additions and refinements are welcomed. There are many other common terms used to talk about hep C that I haven't had time to include in this first instalment. I'll attempt to add to it as the need arises. Hope this clears up a little of the confusion.

Jere Hough, South Florida (jlhough@prodigy.net)

- Abridged with assistance of our Medical & Research Advisory Panel from an article by Jere Hough posted on the HEPV-L email list.



Now I am sane

My name is Christian and I am a French man. Through our international email list, I would like to say hello to all of you.

I am 38 years old, live near Paris and I've been diagnosed with hep C one year ago. I have it since 20 years and got it from IV drug use.

I had a biopsy and the doc told me it wouldn't be painful but it was very painful and they give me very little drugs to eliminate the pain. The biopsy confirmed I had a chronic active hepatitis, but with only very little liver inflammation.

The activity of the hepatitis is also low. I have an activity score of one (the possible range is 1-3), fibrosis score of one (the range is 1-4) and a biopsy score of four. [see 'Biopsies' Ed 20, pg. 28]

My ALT are twice and half the normal rate and I have no symptoms except fatigue from time to time. I had symptoms 15 years ago when if I made a physical effort, my skin was becoming red in the chest and it was scratching me, like an allergy. Now the only thing that I have is dry eyes, I can't wear eye lenses.

I've been diagnosed with non-A non-B hepatitis at the beginning of 1990 but nobody told me that it was a disease. I just thought that it was due to my past activity as an IV drug user, and that I've been ill but now it was gone!

Nor the doctor, nor the lab told me to do something. They perfectly knew that I had a damn virus but didn't let me know about it! When I was diagnosed I consulted an hepatologist who was not fair with me. He didn't let me know anything about it and just told me "How happy you are: you haven't got liver cancer."

I didn't even know that I could have a liver cancer, I didn't know anything about it!

So I decided to go on the Internet to know more about it and what I discovered put the shit out of me. It was speaking of cirrhosis, liver cancer after 20 years of HCV and I'd had it since 20 years ... I lost sleep during 2 months, and when I came back to see him I told him "Do I have a cirrhosis?"

"No, no...": he was an horrible man, too much afraid of the disease, too much afraid of the patient to speak. He told me that he won't put me under Interferon because of my thyroid which seems to be near hypothyroidism.

Then I leave him and I met a doctor which is also a decent human being. Dr Thierry Poynard which is a top hepatologist in the field of the HCV. He told me that he wouldn't put me under interferon because of my fairly good condition of my liver.

Now I am nearly sane. But he told me that if I wanted it, I would just have to ask for it, and that he would be happy to treat me. I think that I would have been put under interferon if I've been into a private hospital - it's good income; the treatment costs about \$7000.

In the public hospital here in France, they don't push you so much under interferon treatment if they don't think you will be in better health after the treatment. I think they are very reasonable. They know that it doesn't work so much and that the effects sides are sometimes bad.

About the social insurance we are very well covered here in France, if you have an hep C, all your costs are 100% refunded. I think in the USA they are more pushing you to be treated and for the labs, it's big buck for them.

People speak more of milk thistle etc., I took Desmodium which is a plant used in Africa against hepatitis. It reduces the ALT and AST, detoxify the liver but doesn't eliminate the virus.

I'm very lucky to be in such a good physical condition despite of 20 years of infection. I wish you all good health.

Thanks for your reading. Bye,

Christian.



Kick dragon ass

I live in the United States and have had some excellent news recently. I have been on the interferon/ribavirin combination therapy for 15 weeks now and my ALT's & AST's have been normal since the 4th week.

At 13 weeks they did a PCR viral count and I just received my blood test results. My viral count is down from 1.5 million at the start of treatment to NON DETECTED.

After 13 weeks of the combo dance, THE VIRAL COUNT IS NON DETECTED.

Sorry for shouting, but I think that just might be something to shout about.

Maybe this will be some incentive for some of you new folks that have just started or are about to start.

I have had very few sides. A little fatigue has been the major issue but even this has not been unbearable.

I have continued to maintain a full time job as a second level manager within a major computer company. Lots of stress and very fast paced, but I had to continue working ... too many dang bills to pay.

Good luck to all of you that are starting the combo. Hang in there. It just might work for you too.

God bless each and every one of the folks on our internet email list. Without my connection to HEPV-L, I would not have made some of the informed decisions that I have made.

Thank you for being there, even though I lurk mostly and I don't communicate a lot, I try to read all of the messages and it has been a life saver for me, literally.

God bless and Kick Dragon Ass,

Pat from Houston



(model/s used above)

Blow this disease apart

Well I'm into day 16 of the Aushep trial at John Hunter hospital. Nine mill units of interferon per day, and the sides have been pretty bad, but seem to be tapering almost into an almost tolerable situation.

I am off work on sick leave until I reduce my dose to 3mill x 3 weekly at the end of this month. It's given me a good chance to think about my future directions and my past actions.

When I was initially diagnosed in 1994 I was advised by various support groups NOT to reveal my hcv status to my work peers. I followed this advice, having to avoid their alcohol infested parties, with vague excuses, but never hitting the nail on the head and really revealing that the reason I drunk in such moderation was that I have hep C (and I'm telling you, these are a bunch of pissheads).

In a lot of cases the peer pressure was too much, and I drank, further exacerbating the cirrhosis that I already have. I have now made the decision that I shall NEVER drink alcohol again - not a drop.

I now feel that not revealing my status was bad advice for 2 reasons:

Now I have no choice but to reveal my status. I have been on sick leave for too long and I now have to back pedal through 4 years of lies and misrepresentations of myself. I have not achieved a thing towards educating my peers about this insidious disease.

Public awareness of this disease is paramount at the moment. how are we going to promote the truth to uninformed people, if we lie about our own status? We must accept the disease with confidence that it can be cured and that our workmates will not catch this disease from us heppers. I am sure that we must be the most "blood sensible" people around.

Tell the world about your hep C. Do not fear discrimination. There are plenty of anti discrimination laws and equal opportunity laws to deal with any crap that may fall in your path. Educate the public and let's blow this disease apart.

Yours in good faith, Jon.

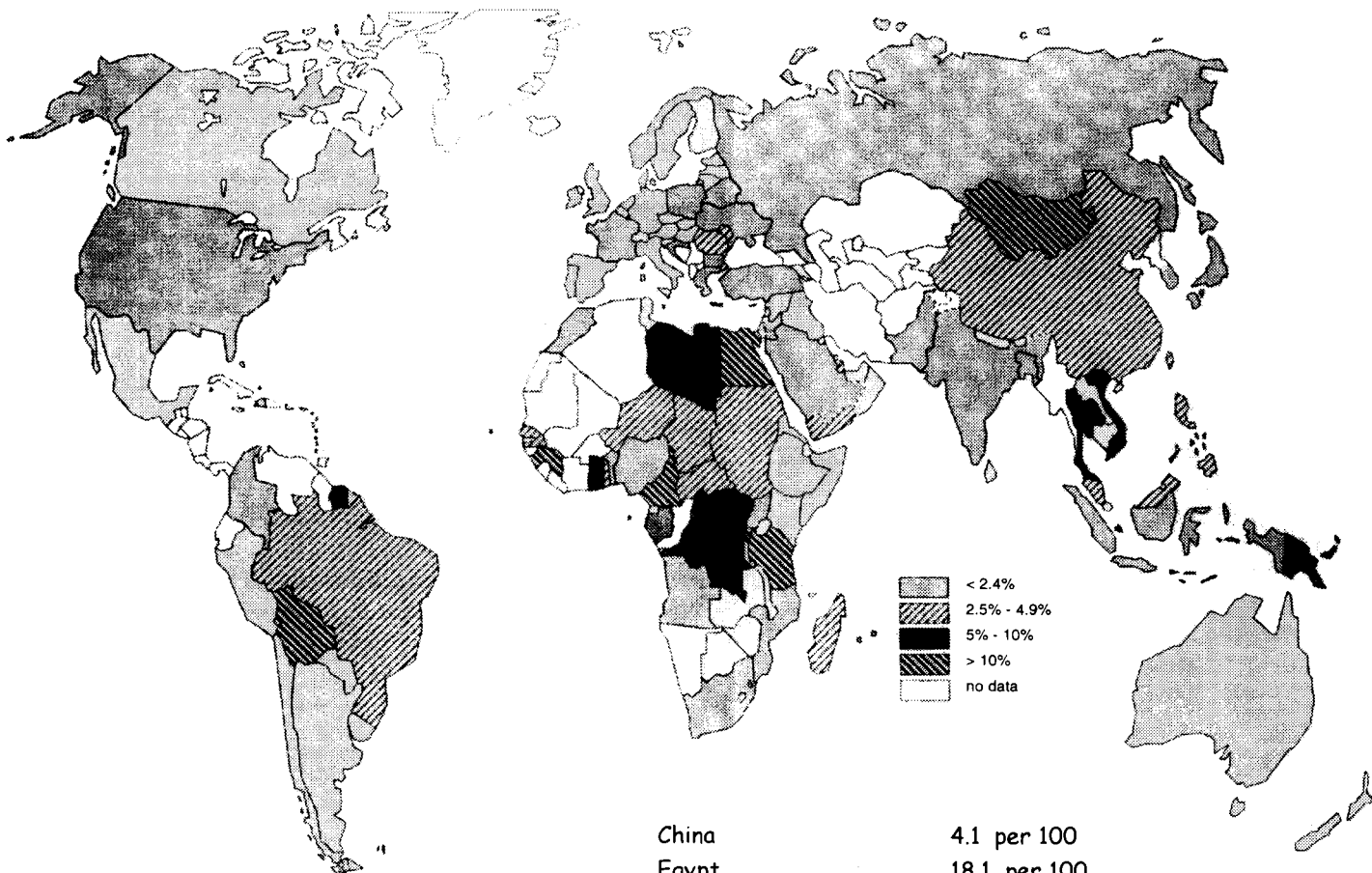
NB: check out our Armidale Musicians club homepage on <http://www.northnet.com.au/~jganders>

and check out our personal homepage on <http://www.ozemail.com.au/~jganders>

Many people experience direct discrimination when they tell others about their hepatitis C. Employers can often find other excuses for sacking employees and a person with hep C may not have a leg to stand on. As individuals, people probably need to think carefully about who they tell.

Some people, though, are more able to be public about their HCV. This is helpful for everyone as it helps confront hepatitis C misinformation that's passed around within the general community and helps address stigmatisation of hepatitis C ... Ed.

The Global HCV Pandemic



Within a single country or region, a serious viral outbreak is usually referred to as an epidemic. When many countries around the world are affected, it is called a pandemic.

Dr C Everett Koop, former Surgeon General of the United States, estimates there are as many as 200 million people with hepatitis C, world-wide.

Similar figures come from the World Health Organisation, who estimate that world-wide, around 170 million people have hepatitis C.

In the case of many countries, researchers have insufficient data upon which to make reliable estimates of HCV prevalence. Overall, it is believed that the estimates above are relatively conservative. For example, the WHO prevalence estimates for Australia are one in every 300 people, whereas Australian researchers estimate that around one in every 100 Australians have HCV.

Some of the WHO estimates include:

Australia	0.33 per 100 people
Brazil	2.6 per 100
Cambodia	4 per 100
Cameroon	12.5 per 100
Canada	1.5 per 100

China	4.1 per 100
Egypt	18.1 per 100
France	1.15 per 100
Greece	1.5 per 100
India	1.85 per 100
Indonesia	2.1 per 100
Italy	0.48 per 100
Japan	2.3 per 100
Malaysia	3 per 100
New Zealand	0.33 per 100
Pakistan	2.4 per 100
Palestine	5.2 per 100
New Guinea	7 per 100
Philippines	3.6 per 100
Russia	2 per 100
Saudi Arabia	1.8 per 100
South Africa	1.7 per 100
Thailand	5.6 per 100
Turkey	1.5 per 100
United Kingdom	0.2 per 100
Tanzania	72.2 per 100 (based on only 1 study)
USA	1.8 per 100
Vietnam	6.1 per 100

- Information taken from the Weekly Epidemiological Record, World Health Organisation, No 46, 14 Nov 1997. Pgs 341-344.

Cirrhosis and muscle cramps.

Abridged from an abstract (overview) of a research project led by P. Angeli, at the Institute of Clinical Medicine, University of Padua, Italy. It was reported in *Hepatology*, 1996 Feb, 23:2, 264-73.

The aim of the study was to define the features, prevalence, and pathophysiology of therapy for muscle cramps in cirrhotic patients ('pathophysiology' is the study of disordered functions or functions modified by disease).

Phase 1 of the study included 294 people with cirrhosis and 194 age- and sex-matched 'controls'. Controls were defined as people without any clinical and laboratory evidence of liver disease.

Features and prevalence of muscle cramps were defined on the basis of a standard questionnaire. As far as the pathophysiological associations of muscle cramps were concerned, the following parameters were evaluated:

- mean arterial pressure (MAP),
- nutritional status,
- liver function tests,
- plasma volume (PV),
- plasma renin activity (PRA), and
- electrolyte, mineral, and acid-base status.

The prevalence of cramps was higher in those with cirrhosis than in controls, and it was related to the duration of recognised cirrhosis and to the severity of liver function impairment.

The presence of ascites, low values of MAP, and high values of PRA were the independent predictors for the occurrence of cramps in cirrhosis.

In the study's second phase, the effects of a sustained expansion of the effective circulating volume induced by intravenous infusion of human albumin were compared with those of a placebo in 12 cirrhotic patients with more than three cramp crises a week. Compared with the placebo infusion, albumin infusion was shown to reduce the cramp frequency.

In conclusion, an increased prevalence of true muscle cramps occurs in patients with cirrhosis. Our data indicate that the pathophysiological link between cirrhosis and cramps may be represented by the reduction of the effective circulating volume. They also indicate that weekly infusion of human albumin may be an effective treatment for cramps in cirrhosis.

- Abridged from information taken from the HEPV-L internet email list.

Alcohol's contribution towards liver damage

Abridged from an abstract (overview) of the research paper, *How much does alcohol contribute to the variability of hepatic fibrosis in chronic hepatitis C?*

The original paper was published in the *Journal of Gastroenterology & Hepatology* 13(4):419-26, 1998 April. The research team was headed by M. Khan and L Thomas. The project was undertaken at the University of Sydney and Department of Gastroenterology, Westmead Hospital, New South Wales, Australia.

In order to determine the contribution of alcohol consumption towards severity of fibrosis in patients with chronic hepatitis C, Khan's team studied associations between various levels of alcohol intake, other demographic variables and liver biopsy results in 434 cases of chronic hepatitis C.

The condition of each person's liver was measured using the Scheuer Score system. Their average daily alcohol consumption for the year preceding liver biopsy (recent exposure) and for earlier periods (past exposure) was categorised into five levels of intake.

One-third of patients gave a history of alcohol intake that had exceeded 4 standard drinks per day for at least 5 years (1 standard drink = a middie of beer, a nip of spirit or a normal glass of wine).

Utilising one method of analysis (univariate), a person's age, but not recent or past alcohol intake or other baseline variables, was associated with liver damage.

Using other methods of analysis (multivariate), however, age, past (but not present) alcohol consumption and birth in Egypt were independently associated with liver fibrosis.

A separate analysis (multivariate) was performed on a more homogeneous (similar) subgroup of 196 people who acquired hepatitis C by injection drug use. In this subgroup, age and past alcohol consumption were shown to be associated with fibrosis.

In analysis of both the main group and subgroup, there was a threshold level of past alcohol consumption beyond which the risk of fibrosis increased significantly - ie. > 8 standard drinks per day.

It is concluded that toxic levels of alcohol exposure for at least 5 years can promote fibrosis in people with hepatitis C, but the influence of alcohol appears to be minor compared with age and other variables. Alcohol's negative effects would seem to occur only at toxic levels of consumption.

- Abridged from the HEPV-L internet email list.

Many readers want to see more detailed information on hep C. The above pages attempt to meet this need. Some research news may appear to contradict current HCV beliefs but such scientific debate is of great benefit,

Hepatitis C virus in West Africa.

Abridged from an abstract (overview) of the research project: *Evidence for high genetic diversity and long-term endemicity of hepatitis C virus genotypes 1 and 2 in West Africa*. The research was reported within the *Journal of Medical Virology*. 55(2):92-7, 1998 Jun.

The investigation was headed by D. Jeannel and C. Fretz of the ICRF Cancer Epidemiology Unit, University of Oxford, The Radcliffe Infirmary, England.

During 1994 and 1995, the prevalence of hepatitis C virus (HCV) and its genotypes were studied in several rural and urban populations in three West African countries: Guinea, Burkina Faso, and Benin.

The following groups of people were screened using the HCV antibody test:

- * 459 villagers in the forest region of Guinea;
- * 965 individuals in urban, suburban, and rural populations of the Bobo Dioulasso area, Burkina Faso; and
- * 582 blood donors in Cotonou, Benin.

(In Benin, 60 people with sickle cell anaemia were tested, half of whom had received multiple blood transfusions. Thirteen hospital patients with liver disease were also tested.)

People who had returned positive HCV antibody tests then had PCR viral tests done, followed by genotyping and sequencing of unrecognised subtypes. The prevalence rates of anti-HCV were 1.1% in the Guinean population group, 1.4% among blood donors in Benin, and 4.9% in residents of Burkina Faso.

Of the people with sickle cell anaemia, five of the 30 multiple blood transfused patients (17%) were HCV antibody positive, whereas none of the other people with sickle cell anaemia who had no history of blood transfusion were antibody positive.

Among the 13 people with liver disease, five were HCV antibody positive, of whom four had history of blood transfusion.

HCV-RNA was detected in 41 anti-HCV positive blood samples. All belonged to genotypes 1 or 2, with a high level of diversity; 18 different subtypes were identified, including 2c, 2d, and 16 new subtypes.

Such genetic diversity poses a challenge for vaccine development and also implies that HCV infection is long-established in these West African regions.

- Abridged from the HEPV-L internet email list.

Does coffee raise ALT?

A study reported in the *British Medical Journal* has researched the effect on liver function of drinking plunger coffee (made by pouring boiling water over ground coffee in a container with a sieve plunger). The effects were measured in terms of people's blood level of alanine aminotransferase (ALT).

Dr Rob Urgert's team at Wageningen Agricultural University in the Netherlands had 22 people drink five to six cups of plunger coffee each day for 24 weeks while 24 other people drank the same amount of filtered coffee. The amount of caffeine in each cup was identical for both groups.

People's 'baseline' levels of ALT were determined prior to the drinking of the different coffees, above. Dr Urgert observed that in the group who drank plunger coffee, ALT levels rose by up to 80% (above baseline).

ALT levels exceeded the upper limit of normal in 8 of the 22 subjects who drank plunger coffee (in at least one of the ongoing monitoring tests) as opposed to only 1 of the 24 who drank filtered coffee.

The investigators attribute the increases in ALT levels to substances that are abundant in coffee (*cafestol* and *kabweol diterpenes*). Dr Urgert's team notes that these diterpenes are removed when coffee passes through paper filters, a process that does not take place when brewing plunger coffee.

Dr Urgert believed that within the first 6 months of daily consumption of plunger coffee, liver cells only partly adapt to coffee diterpenes. Because other research showed that long term plunger coffee drinkers didn't have elevated ALTs, he did not believe the injurious effect of coffee diterpenes was ongoing.

On this basis, the researchers questioned whether drinking plunger coffee poses any risk of liver damage in people who don't have pre-existing liver problems. They noted that in Scandinavian countries where patterns of coffee drinking have changed over time from plunger coffee to filtered coffee, low death rates from liver cirrhosis remain unchanged.

Dr Urgert believes that it may be prudent for patients with raised ALT levels (eg. due to hepatitis C) to drink no more than a few cups of strong unfiltered coffee a day on a regular basis.

The researchers were not able to say that sub-clinical injury to liver cells (damage that wouldn't show up within ALT level monitoring) does not occur. Drinking percolated or instant coffees would be preferable because of their low concentrations of coffee diterpenes.

- Abridged from the original study published in the *BMJ* (1996; 313:00-00).

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leading to a better understanding of HCV and its affect on people's health. To clarify any medical terminology, or for further information, please speak to your doctor or specialist, or phone the Hep C Info/Support Line.

My guy

I met a man one day at my parent's home where I was then living, five long years ago. He was my brother's friend and seemed nice.

Later, I saw him in a shopping centre and he seemed ill - so different. I persisted and finally, my brother finally admitted that his friend was doing heroin. I cried and cried and cried.

Then I asked my brother for his friend's telephone number. My brother urged me to have nothing to do with him but I had such horrible images going through my mind - of overdose and death. And I wanted to let him know that I cared.

I finally managed to meet with him and this meeting later led me to standing by him whilst he recovered from his heroin addiction.

It was very difficult. I got tired and was confused. I had no prior experience with drugs and the sleepless nights by his bed when I stood by him and supported him took a toll on me. I chose to spend some time apart from him.

Whilst under the influence of drugs, he got into trouble with the law. After time, whilst in jail he quit heroin but he'd become physically addicted to sedatives, tranquillisers and was also taking antidepressants.

Almost four years had passed since we'd first met but so many horrible things had happened. Gone was my innocence and my rose tinted glasses. I was tired but he needed me.

It took months for him to get off all these prescription drugs. I hated them. I asked psychiatrists for help but he only went to one, once. He wanted to get better on his own - he didn't want 'help'. But then from tranquillisers, he went to alcohol and we fought.

He cut down on the alcohol. He told me he loved me more than anything - and anyone else. I knew I loved him but my nerves weren't doing well. My mind was strained. My hopes and dreams seemed so far away.

He asked me to be patient and things would work out. By this time, I was so attached to him, I don't think I could have left him even if I wanted to.

Eventually, he regained his health. He was happy, working and earning money. He was even supporting me. Then one day he was diagnosed HCV+. I cried.

I cried because he went through so much suffering. He tried so hard for so long to quit the drugs, to find a job, to live a decent life and be someone who his family could be proud of. And then the HCV.

Some people would think it serves him right and I shouldn't have been involved with him in the first place. Some people may think I am a fool - but I'm in love with him.

I wish there wasn't so much prejudice and fear around HCV. I wish there was more public awareness and sensitivity. I wish there was more support.

I can't say I know what it's like to be to be addicted to heroin or any other drug, or what it's like to be in jail, or the stigma of having been in jail. But I do know what it's like to love someone who is hurt, afraid and suffering - and it hurts me.

Maybe some HCV+ people will read my story and think of their wives, husbands, girl/boy friends - think of their feelings. Maybe HCV+ people's partners will feel there are others who share their experiences - of frustration, exhaustion, concern, love and hope.

I'm still hoping my beautiful man will find the strength to continue his life in a healthy, happy way, regardless of HCV because he is so tired and concerned.

I hope all those HCV+ people who are or were drug users do not feel ashamed of themselves because of their drug use, and that those in prison or ex-prisoners know that they are just as good as everyone else.

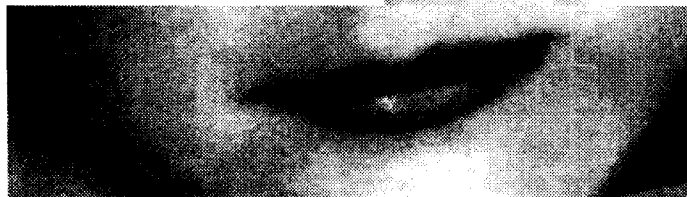
It seems I have quite a bit rolled up in one man, and I hope your prayers will be with us as we strive to live a full life regardless of HCV and regardless of people's attitudes to drug use and prison.

I will be hoping for all people to move beyond these things and consider how beautiful our country is and how beautiful life is.

Before I read *The Hep C Review* for the first time, I felt alone, but talking with the volunteers and reading other people's stories in the *Review* has given me strength once again to move on and I thank you all for that. Even those people who wrote looking down on drug users and prisoners because they too are important and have their story to tell, their own pain, hopes and fears. And if they don't understand the rest of us, maybe one day they will.

I do love you all

June



✦
(model/s used above)

European Assoc. for the Study of the Liver

The 33rd annual meeting of the European Association for the Study of the Liver was recently held in the Portuguese capital of Lisbon. Doctors and scientists from all parts of the world converged to discuss and debate the most recent developments in the diagnosis and treatment of liver disease.

At the meeting, there was much debate on the application of viral load testing for HCV with some speakers advocating such testing on an individual basis, while others supported its use on a broader scale across patient groups.

The consensus of opinion was, however, that the use of viral load measurement in the management of hep C will bring benefits to both the patient and treating physician.

Combination therapy for hep C is currently being exhaustively studied in clinical trials. Dr Graham Foster, Imperial College of Science, Technology and Medicine at St Mary's Hospital, London, described some very encouraging results using amantadine alone, and in combination with interferon.

Amantadine was originally introduced during the 1960s as an antiviral treatment for influenza, and has also been used to inhibit Dengue virus, which is closely related to HCV and which also causes liver damage.

Monotherapy with amantadine for people previously relapsing on interferon, has given conflicting results, he said, with viral clearance being shown in some studies, but no change in viral load being observed in others. However, combination of interferon plus amantadine has produced 30 percent viral clearance in people failing on interferon monotherapy.

In a small study, the triple combination of interferon, amantadine plus ribavirin showed an excellent initial response in 70% of cases, which was maintained after termination of therapy.

Dr Foster then described a study of people who'd had no previous hep C treatment. These people had moderate to severe disease but did not have cirrhosis, and were treated with either interferon alone or the interferon/amantadine combination.

This twelve month study was still underway but at three months, 50% of people receiving interferon alone showed as PCR negative compared to 75% of

those on the combination. There have been no relapsers in this arm of the study to date, however, larger studies are needed to confirm these results.

A surprising and important finding during the investigation has been that people receiving the combination treatment have not reported the usual interferon-associated side effects of depression and fever.

These results have been so encouraging that 280 patients have now been enrolled in a multicentre study. Dr Foster suggested that amantadine may well be the perfect partner drug for interferon.

Within a general session on the final day of the conference Dr Alfredo Alberti, University of Padova, Italy, extensively reviewed the current state of hepatitis C therapy. He said that with the advent of new drugs, 1998 could be a turning point for treatment for hep C.

The decision of when and whom to treat for hep C is still far from clear, but there was agreement on some preliminary guidelines: for example, people who were HCV positive with normal ALT levels should not be treated, but those with chronic hepatitis without cirrhosis should be, since interferon treatment has been shown to delay cirrhosis.

Factors such as age, grade of liver inflammation, stage of fibrosis, and duration of disease should all be considered when making treatment decisions. In addition, HCV viral load and genotype data were seen as important as well. In cases of compensated cirrhosis, there are no firm present recommendations.

The next question Dr Alberti considered was the choice of treatment schedule. He said the consensus now is for a period of one year of treatment, with some variation in the dosage used (3-6 million units), and a withdrawal of treatment after three months if no response was forthcoming.

In his opinion, response was best measured using viral load, and he identified several studies in his review of the data. It is now known that a rearguard action by retreating non-responders with interferon alone is not efficacious, and is therefore not recommended. On the other hand, re-treatment of relapsers with high dose interferon can result in sustained response.

He added that the combination of ribavirin with interferon prevents relapse, in a number of patients. In addition, in HCV infections other than genotype 1, very high rates of cure had been achieved with the interferon/ribavirin therapy (90 percent in genotype 3, compared with 24 percent in genotype 1).

The combination of high viral load and genotype 1 would need a new strategy - possibly high daily dose interferon with or without ribavirin and/or amantadine, since these experimental regimens are currently giving encouraging results.

However, Dr Alberti made the point that at present there does appear to be a sub-group of people with hep C who do not respond to any available treatment.

He concluded by looking forward to the new millennium when a new series of drugs will become available such as serine protease inhibitors and RNA helicase inhibitors, which will provide new treatment strategies for hep C.

- Abridged from *Congress Reporter* 1998 EASL33



400 sue over infected blood

By Roger Dobson, *Independent on Sunday*, UK

The British National Blood Authority is facing a multi-million pound claim for damages from more than 400 people, some of whom are dying of liver damage, who claim they were given blood infected with hepatitis C.

Lawyers say Britain failed to introduce a test for hepatitis C when one was available and being used in other countries. It is claimed that some kind of testing was available for nearly four years before a test was introduced in the UK in 1991.

So far, 160 people have signed up to the lawsuit, but the number of people taking action is expected to reach 400 by the time lead cases are selected for trial later this year, said solicitor Anthony Mallen, who is coordinating the action.

The case, the first of its kind under the Consumer Protection Act, centres on people who say they were infected with hepatitis C through blood transfusions between 1988 and 1991 (when the antibody test was brought in).

Hepatitis C virus is a blood-borne infection causing inflammation of the liver and is the most common cause of chronic liver disease. One problem with the disease is that 90 per cent of people show no symptoms when first infected. Random sampling of blood tests indicate that the disease is now so prevalent that about 500,000 people in the UK may have it.

"The essence of the claim is that this country should have brought in testing earlier," said Mr Mallen.

"We say that the Consumer Protection Act creates strict liability or absolute liability. We say that blood products are products within the meaning of the Act and that those products were defective because of the contamination with hepatitis C.

"If that is established it is incumbent upon the defendants of the National Blood Authority to prove that there were at the time no scientific methods available to exclude this infection of blood. In other words, once we have proved it is a product, the burden of proof transfers to them."

A spokesman for the NBA referred comment to the Department of Health, which declined to comment on the case.

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- Taken from the HEPV-L internet email list.

UK care fails those with hep C

Up to 400,000 people in the UK are infected with hepatitis C, yet most are unhappy with the way the health service treats them.

The figures have been released as campaigners seek to raise awareness and improve management of the disease.

Findings from two surveys suggest that while up to 400,000 people are infected in the UK, only 10% of health authorities and boards have developed measures to prevent and treat the disease.

The British Liver Trust released the figures on Monday alongside the launch of the campaign project, *C Change*.

The trust funds research and offers support to patients diagnosed with hepatitis C. It asked 637 patients for their opinions on the quality of the care they had received.

Overall, the people with hepatitis C interviewed said GPs' knowledge was poor.

Forty per cent said they were given the diagnosis of hepatitis C in an uncaring and insensitive way and 90% said they were not given enough time to discuss the diagnosis.

Neither help nor counselling was offered to 75% of the patients surveyed, the findings show.

More than 65% said they thought their GPs lacked up to date knowledge of the disease.

The trust also questioned all 124 health authorities and boards in the UK - 89 replied. Their response showed that while 20% had a published strategy for tackling the virus, only one in 10 had drawn up a comprehensive policy for hepatitis C prevention and treatment.

Less than seven per cent of the authorities thought the disease was a high health priority, but double that number thought it was a serious cost issue.

C Change is formed of liver doctors, nurses with a specialist interest in hepatitis C, patients and care workers involved in the treatment of the disease. Chairman Christopher Buckler said: "The results of these two surveys were extremely disappointing although not unexpected.

"We know from direct contact with patients with hepatitis C that both primary and secondary health care is often failing to address the needs of patients."

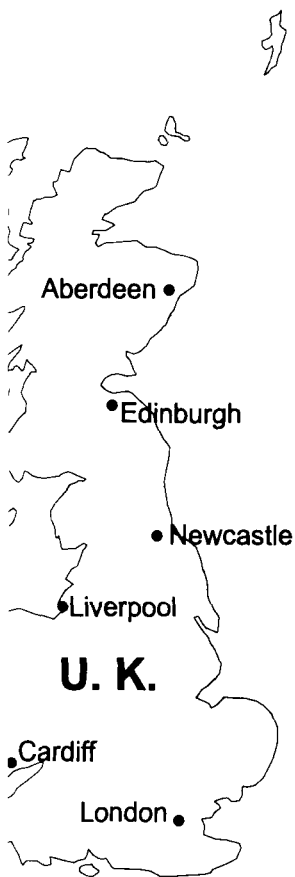
- Abridged from information taken from the HEPV-L internet email list.



Prison drug problem may be driving hepatitis epidemic

Jenny Booth, *The Scotsman*, UK

Scottish prisons may be fuelling the country's hepatitis epidemic, a drugs expert has warned.



Dr Laurence Gruer, addictions co-ordinator at Greater Glasgow Health Board, says Glenochil prison - where 19 inmates contracted HIV and 15 were infected with hepatitis B in 1993 - and other jails could be accelerating the spread of hepatitis strains across Scotland.

Dr Gruer was commenting on a new survey which shows continued dangerous levels of needle-sharing among drug injectors in Scottish jails.

The Scottish Prison Service was not doing enough to tackle the very high number of inmates who continue or even start to take drugs behind bars, he said.

"Prisons certainly could act as a driver for new hepatitis B epidemics.

"So there is more risk of prisons acting as a driver

for its spread in the wider community. It is also fair to say that prisons would certainly be contributing to the spread of hepatitis C.

"I am sure that the SPS isn't doing enough to provide education and drugs services. It isn't because of lack of recognition of the problem, it's just not seen as an urgent priority."

But the SPS denied that it was being complacent, and announced it was about to start a pilot project at Greenock prison offering all new inmates vaccination against hepatitis B.

Michael Mulford, a prisons service spokesman, said: "The proposition that using dirty needles in prison is

fuelling a hepatitis outbreak in jails and beyond has no hard scientific evidence to back it."

Dr Gruer spoke after the publication of the *Third Scottish Prison Survey*, for which 4,780 inmates were questioned. The survey shows that more than 650 prisoners admit to taking heroin behind bars in the last six months, with 237 injecting the drug.

Nearly 200 shared needles and syringes, making it almost inevitable that they will infect each other with hepatitis C, a virus shared by an estimated 70-80 per cent of Scottish drug injectors. Injectors are also at high risk of contracting hepatitis B - a disease that they may sexually transmit to their partners in the wider community.

At Glenochil, Inverness and Low Moss prisons and the National Induction Centre at Shotts, all drug injectors are sharing needles.

"It is concerning that in Glenochil 100% of injectors are sharing works [needles and syringes], as Glenochil was the place where in 1993 there was the first fully documented HIV epidemic in a prison anywhere in the world," Dr Gruer said.

"The problem with prison is that there is evidence that some people will start injecting in prison, with nothing better to do.

"The chances of contracting hepatitis C in prison if you have never injected before are very, very high indeed.

"Works are likely to be shared with lots of people anyway, and there is no adequate way of cleaning syringes that get pretty ancient and rusty. Viruses can hang around in the nooks and crannies of these old needles."

Dave Liddell, the director of the Scottish Drugs Forum, said the prison survey figures on needle-sharing were a big cause for concern.

"What we saw in Glenochil before was the very rapid spread of HIV among a group that shared injecting equipment. Hep C is much more virulent than HIV and the risks are very much greater.

"It may be that given the level of sharing in prison, prison plays quite a strong part in the level of infection in Scotland."

The inmates most anxious to inject heroin were those who were suffering serious withdrawal symptoms - particularly from NHS methadone.

Both Dr Gruer and Mr Liddell said the survey results made it urgent for more prison doctors to consider continuing methadone prescriptions to drug addicts who have been receiving it in the community.

Glenochil does prescribe methadone, but most inmates serving short sentences are offered little or no help, a fact that has contributed to a number of suicides.

"The absence of methadone prescribing is another major, major gap in the prison approach to drugs, which they are very slowly coming around to recognising," said Dr Gruer.

The one policy that would prevent the spread of hepatitis - providing sterile needles and syringes in exchange for dirty ones - has been ruled out because of the risk of infected needles and syringes being used as weapons.

The prison survey showed that the drug users admitting to taking heroin behind bars has risen from 9 per cent in 1994 to 31 per cent this year.

- Taken from the HEPV-L internet email list.



Combo the dragon

I live in the United States and have seen a lot of questions on the internet about starting combination therapy or not.

I have been suffering with mild depression for years on and off. There was a mixed bag of reactions by my internist and the gastro as to whether to start me on the medicine or wait. I wanted to have the medication desperately as the interferon didn't work the first time or the second time with increased dosage on it.

I feel it's my life and I want to have any and all chances to have a long life that is not full of pain or fear.

I have been on combo now for about 3 weeks. I had a month hospitalisation prior to this for chest pains. When I came out I had to start the whole process at the beginning.

Some people can do the dance (treatment) without too much inconvenience. Others like myself suffer side effects from HELL.

One of the worst for me is the panic attacks that just started about 2 wks ago. I am on medication for them, but I won't stop the combo therapy until I have no other choice.

My liver functions are coming into the normal range for the first time in 5 yrs and I want to give the best I can to beating this dragon.

For people still confused about starting or not remember you are the only one who really knows your body and mental state. Find out all the information both pro and con about the medicine and talk to people who have been on it.

Get as much truthful info from the internet bulletin boards/lists as possible and read everything you can so when you make your decision it will be one based on logic and not just emotion.

Good luck to all who try it and for those who don't there is always the future research that might come up with something for you.

Love, Maureen



✦
(model/s used above)

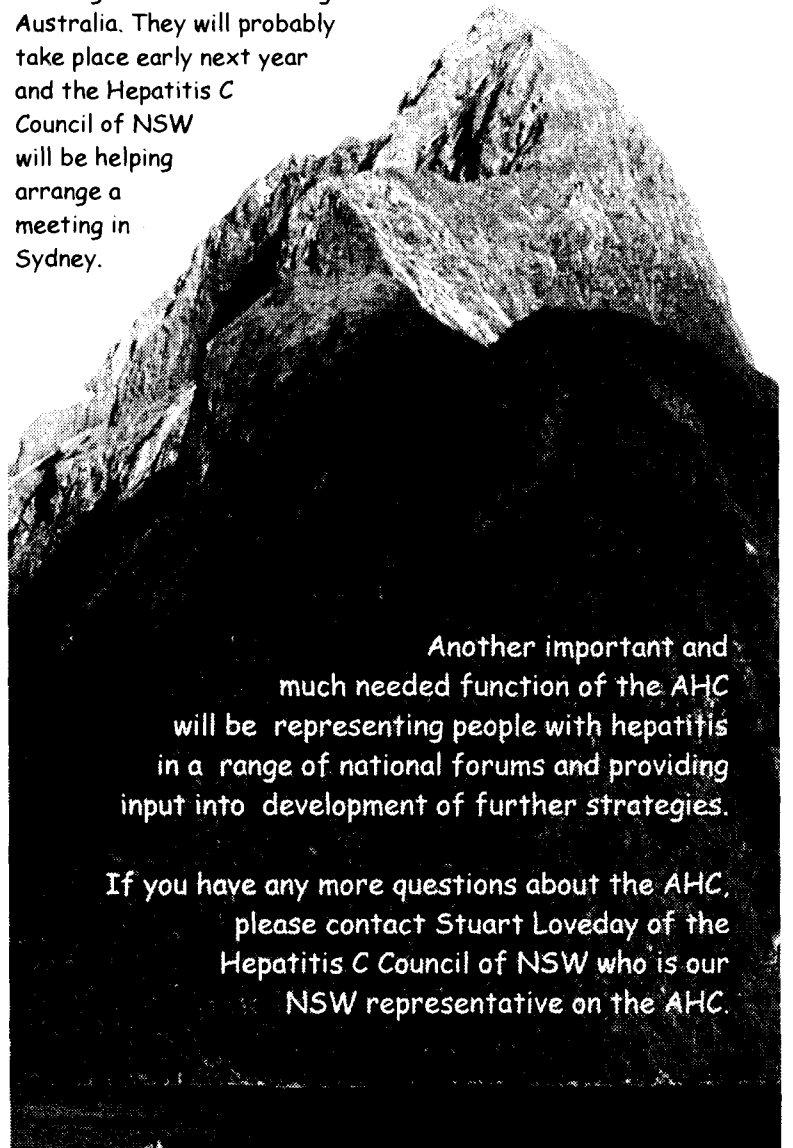
New national peak body formed

The recently formed Australian Hepatitis Council (AHC) is made up of representatives from the various state and territory hepatitis C Councils and has two staff: Jack Wallace being the Executive Officer and Michaela Colebourne as the Education Officer.

Funded by the Commonwealth Government the AHC aims to produce resources that include a newsletter, an HCV testing information booklet and a booklet giving health maintenance and monitoring information.

The AHC has also been asked to develop an Educational Strategy targeting people with HCV that will assist the state/territory based Councils in planning.

In developing this Educational Strategy, meetings will be held throughout Australia. They will probably take place early next year and the Hepatitis C Council of NSW will be helping arrange a meeting in Sydney.



Another important and much needed function of the AHC will be representing people with hepatitis in a range of national forums and providing input into development of further strategies.

If you have any more questions about the AHC, please contact Stuart Loveday of the Hepatitis C Council of NSW who is our NSW representative on the AHC.

Hepatitis C: The Neglected Epidemic

The NSW Parliamentary Standing Committee on Social Issues has tabled a major, comprehensive report into hepatitis C.

Parliamentary tabling and public release of *Hepatitis C: The Neglected Epidemic* coincides with rising community concern about hepatitis C - as indicated by recent hepatitis C coverage on ABC News, and the *60 Minutes* and *Witness* current affairs programs.

Of the report's 131 detailed recommendations, key conclusions can be grouped into the following five areas:

Policy & strategic planning

It is imperative that policies and strategic plans are developed to direct all facets of hepatitis C including support, treatment, management and prevention. This commitment to sound hepatitis C policies must be evident in upgrading the current Hepatitis Advisory Committee to a Ministerial Advisory Committee on Hepatitis C; designing, developing and implementing a NSW Hepatitis C Policy Statement and a NSW Hepatitis C Strategic Plan; providing adequate and ongoing dedicated funding to implement the Statement and Strategy; and appointing Area Hepatitis C Managers to the five Area Health Services with exceptionally high levels of hepatitis C notifications.

Preventing HCV transmission

Strategies to prevent the transmission of hepatitis C must be broad and multi-faceted. The Committee fully supports the concept of harm minimisation and considers it to be the most effective underlying principle for strategies to prevent the transmission of hepatitis C amongst injecting drug users. It is the basis upon which the Committee framed all recommendations directed at injecting drug users (both in the general community and the state's correctional system).

Prisons

The Government must recognise that inmates within the state's correctional system face an unacceptably high risk of contracting hepatitis C and, on release, may pass on the virus to others in the wider community - through injecting drug use. These

circumstances warrant radical policies to reduce inmates' exposure to hepatitis C. The Committee proposes a broad range of prevention strategies; the introduction of a Best Practice Model of treating hepatitis C amongst inmates and the implementation of a strategic plan to manage hepatitis C in the correctional system.

Further research

There is an urgent need for further research to be undertaken in a number of areas, including: ascertaining the incidence and prevalence of hepatitis C in the general community as well as in specific population groups such as injecting drug users and prisoners; developing an empirical [research-based] understanding of the personal, social and economic impact of hepatitis C; research into the causes of hepatitis C related discrimination; clinical studies to identify and understand new treatments for hepatitis C and the impact upon patients (particularly female patients) of these new, and existing, treatments; an understanding of the interaction between methadone and interferon and the impact of methadone on pregnancy; research into a range of injecting drug related issues; and studies into the effectiveness of complementary therapies to treat the symptoms of hepatitis C.

Community awareness

There appears to be limited understanding in the community about hepatitis C, in particular, about the way in which it is transmitted. Many assume it has the same transmission routes as other blood borne viruses such as HIV/AIDS. Health care workers, including medical specialists, often have a poor understanding of the disease. This lack of understanding manifests itself in a number of ways including discrimination and stigmatisation towards those with hepatitis C, frustration by those with the disease as they struggle to learn about the disease and sort through conflicting information, and a lack of compassion and tolerance in the general community.

To redress this situation, Committee Members have called for the introduction of a number of strategies including education campaigns targeting all those working in the health care sector and public service, the production of an information brochure informing those with hepatitis C of their legal rights and action they can take to address discrimination, support for the National Hepatitis C Education Program for General Practitioners which seeks to inform and educate general practitioners, and a national community hepatitis C educational campaign.

For further information

All people who made submissions to the Inquiry will be posted a copy of the report. If you are one of these people and have changed your address recently, please contact the Inquiry on 02 9230 3435 (ph), 02 9230 2981 (fx) or emailing cknight@parliament.nsw.gov.au

If you didn't make a submission but want to see the report, contact the Inquiry committee (see above contact details). Alternatively, phone your nearest university library to see if they have a copy you could view.

Alternatively, look for the report at the following webpage:
www.parliament.nsw.gov.au/lc/committs/socissue.html
You should not need the prefix <http://>

A global snapshot

In an attempt to find out what's happening overseas, we circulated a series of questions via various internet email 'lists'. We've received the following personal opinions from people around the globe:

Personal views from America

Does your government have some form of coordinated comprehensive HCV strategy?

No. The Centre for Disease Control is more or less saying that this is a disease of IV drug users and people who sleep with more than one person thereby taking a moral ground that this disease only happens to people that God wants to punish, i.e., the demonization of HCV exactly as it did with HIV.

What transmission prevention initiatives have been adopted in your country (eg needle exchange)?

Needle exchange is done by volunteers. Federal and state governments have been unwilling to get involved because of the reaction of right-wing religious groups and the Republicans who pander to them again making this a moral issue.

Do you have national or state HCV community based organisations?

The American Liver Foundation and Hepatitis Foundation International are national in scope and collect money for HCV research. Due to the structure of non-profit groups, grass roots organisations like the Hepatitis Education Project are limited to communities within the state.

Do you have free access to PCR testing in your country? (viral detection, viral load, viral genotype)

The PCR qualitative test is used as a confirmatory test and costs in the neighbourhood of \$US 250. Viral load and genotype are only ordered in rare cases because insurance companies in general do not cover the cost.

If so, are there any limitations?

Must be ordered by a physician and only if the physician can justify the cost to the private health insurance carrier.

What hep C treatments are available in your country?

The Food and Drug Administration have approved two treatments; 1. Interferon for up to 18 months for naive patients (those who've not had interferon before) and 2. Interferon plus Ribavirin for patients who did not respond to interferon alone.

Are there any restrictions on treatment?

Depends on the health insurance company. Some Health Maintenance Organisations make it very difficult to obtain treatment and the patient often has to threaten civil litigation. People without health insurance do not receive treatment through welfare or Social Security. Sometimes the County Health Department in which they live provide low cost access.

Do your healthcare authorities support or promote alternative therapies for hep C?

Absolutely not.

In your country, do hep C people experience hep C related discrimination or stigmatisation?

Yes. Some people have lost their jobs. Others have lost a marriage or relationships with family and/or friends. The CDC keeps pounding home the message that this is a disease of junkies, perverts and prostitutes making the Federal Government complicit in discrimination.

If so, have initiatives been implemented to address discrimination?

None that I am aware of.

Is there anything else you want others to know about the HCV response in your country?

Ignorance still reigns supreme in the general population and with primary medical personnel. When people hear "hepatitis" they think HAV or HBV. More education needs to be done before people are aware of the nature and transmission risks of HCV.

A second American personal view

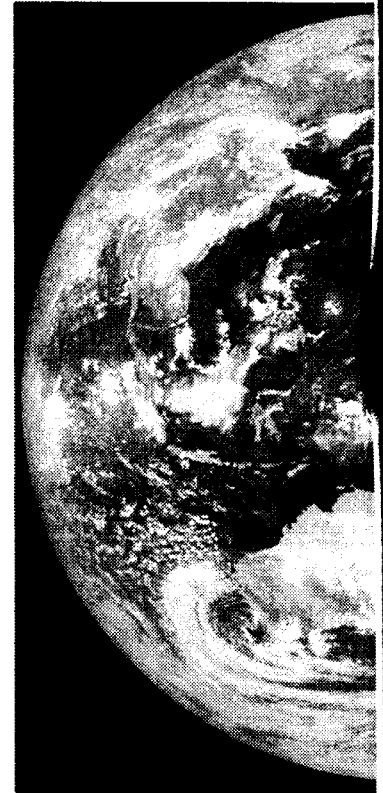
In regard to a coordinated comprehensive HCV strategy, yes, the government is starting to work on public education.

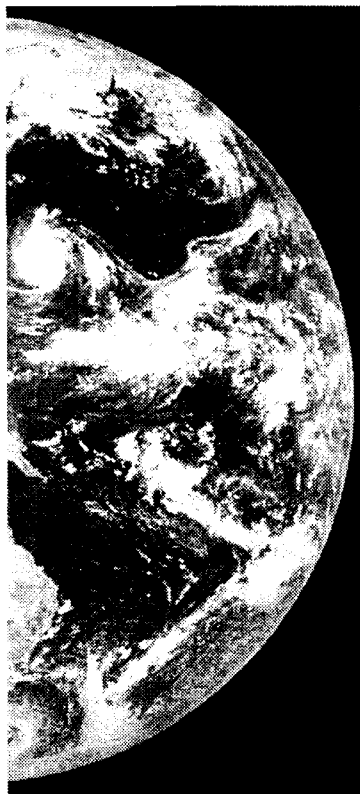
Additionally, increased money is going into HCV research. Recently, it was announced that funding has doubled since 1994 (from US\$6.2 to US\$11.9 million). A large part of the increase went to establishing the Hepatitis C Cooperative Research Centres. The National Institute of Health are also committed to ongoing HCV research.

My kids are also learning about hep C in school and the authorities are also going to be notifying blood bank donors whose blood has the virus.

We don't have needle exchange. Instead, there is an emphasis on education.

Here in the States we have several HCV organisations. They include: The American Liver Foundation and The Hepatitis C Foundation. International internet organisations based in the US include: Hepatitis





Foundation International, Heponline and Hep C Alert.

Across the US, we also have many local hepatitis C support groups. Often people host the meetings at home, or they are held at hospital meeting halls or restaurants.

We don't have access to any type of free HCV testing. For some people, the only way we know of to get tested free is to donate blood, and then wait to find out.

Interferon and ribavirin are available in the US. People have to be interferon

relapsers before trying the combo treatment and they should be free from cirrhosis. People have to have big bucks or insurance ... treatment is expensive!

No herbal treatment has been offered with adequate testing. Doctors are very closed-minded about anything outside of the medical model. VERY closed-minded.

In the US, people do face hep C related discrimination. Mainly this is happening in the workplace.

Overall, our hepatitis C response is slow. It looks like it has been calculated this way. Smells like bad fish to most of us.

A personal view from Denmark

Denmark is a country in northern Europe - it is part of Scandinavia. Around 15,000 people are considered to be infected with HCV - that is approx. 0,25% of the inhabitants. We have formed a nation-wide support group, featuring a telephone support network operating from our home. It is entirely private, no sponsors - no help.

Our government has no form of coordinated comprehensive HCV strategy. They don't consider this to be a general public threat, we were told to-day. Nothing, therefore is done in order to enlighten people and no general screening.

In Denmark, to help prevent HCV transmission, IV drug users can get free needles. In regard to other prevention initiatives, there are none as far as we have seen.

There are no national or state HCV community based organisations in Denmark but my husband and I have started the first private webpage in the whole of Scandinavia.

You asked, 'do people with HCV have any type of free access to PCR testing in your country?' Yes, we do have free access to PCR testing but the doctors do not include genotype and we are not being informed about the viral load. In fact we have in writing from a leading epidemiologist that they don't consider the genotype of any importance.

For treatment, we have interferon - and the combination therapy of interferon+Ribavirin. These treatments and all medical care are free.

The combo therapy is limited to those who have tried interferon without success.

Our healthcare authorities do not support or promote alternative therapies for hep C.

In Denmark some people experience hep C related discrimination or stigmatisation, others don't. We have been open about it ourselves and try to tell people what it's all about. Other people we know of tell us that they do meet ignorance and some minor discrimination.

Within the hospital system there seems to be only relatively few who assume that HCV can only be contracted if you are a IV drug user - or former IV drug user. Most healthcare workers are aware that other risk factors exist.

Our group has carried out a personal "crusade" through newspapers and national television - telling people about the potential risks - and advising that dentists ought to have autoclaves installed (as a compulsory thing). Until to-day only 1/3 of the dentists have autoclaves on a voluntary basis.

We tried to address the present Minister of Health about this but the Ministry of Health Department and their officials rejected to make this obligatory. Members of Parliament tried to talk our case (but for personal publicity) but did not succeed.

We have been writing articles that are being published now and then - and our website has brought a lot of attention. Links to the site even from the Ministry of Health. Our aim is to make HCV a socially acceptable disease - and not just a disease connected with IV drug users.

Our website, "The Danish Hepatitis C-website", is at:
<<http://home3.inet.tele.dk/omni>>
and our email address is: <omni@post3.tele.dk>

A personal view from the UK

Hi, I have been involved in HCV support for the last 7 years in the UK - mostly in Scotland.

I can give you some answers, but they are an informed patient's answers. Anyhow here goes:

feature

Our government has no form of coordinated comprehensive HCV strategy. It's our biggest political hot potato!

Needle exchanges are pretty standard here, but there's still not enough of them, nor used enough or promoted enough. Each small region does a pathetic attempt at education (or not) and sadly the information is seldom unified. A very few initiatives exist specifically for prevention or harm reduction, and are scattered through UK.

We don't have a national HCV community based organisation but there is Mainliners. It was HIV/ drugs based and has included HCV in their remit. The British Liver Trust attempts to deal with HCV through support groups, and certainly the number of HCV support groups outnumber other liver disease greatly, and rises every year. But no specific charity exists at present.

In theory we have free access to PCR testing but there are limitations. If you are a drug user past or present, it can be difficult to be given the same attention as 'others'. If you live in an area that does not have a liver specialist or hepatologist at the local hospital or enlightened GPs, then ignorance rules the day! I have dealt with many people denied any form of diagnostic or curative treatment whilst drug taking or on methadone programs, similarly alcohol patients can be given a hard time.

In regard to licensed hep C treatments, I 'think' its just interferon. Ribavirin is on trial in my region, as is amantadine in other parts. Anti oxidant treatment is proposed as another trial. I am sure I have not included all facts here.

There are restrictions on treatment. It depends on what doctor or area you live. Some doctors believe early treatment to be best, others prefer to wait until things go wrong. Contraindications are open to wide and general interpretations - like the depression issue of interferon. Some believe that it is positively dangerous to give this drug to anyone with a mental health history. Others minimise these side effects and prescribe rashly. Money of course is the biggest limitation.

Very few of our healthcare workers support or promote alternative therapies for hep C. I only personally know of two in UK, one in Huddersfield and one in London, but that doesn't mean that there aren't more though.

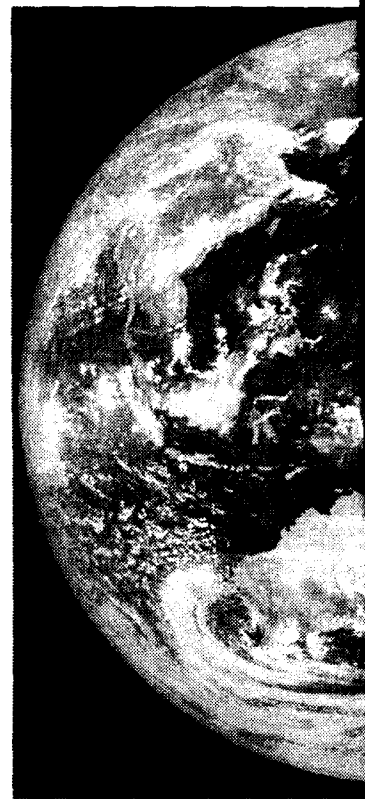
Many people here are open to discrimination. A very recent TV program decided to highlight the risks of transmission, and added saliva to the list. My phone, and those of The Trust have been ringing with anxious people asking if it's safe to kiss their children, or drink a cup of coffee in a friend's house.

Funeral Services are sadly the most tragically uneducated, and most capable of causing most distress. They are advising families to not view the body. They won't embalm. They sometimes won't take the body out of a body bag. They won't open the coffin, and they often tell families that HCV is still highly contagious even in death!

This issue goes on and on, and is not very different from one part of the world to another I don't think.

I am sure a few local support groups have tried to apply pressure to combat discrimination, and Mainliners work hard at this stuff. There's nothing that I am aware of done 'officially' by the government.

In closing, we all need to stick together on this and educate the world, en masse! One virus, one message, one understanding. I hope this has been helpful.



Another personal view from the UK

The British government has no form of coordinated comprehensive HCV strategy, and needle exchanges exist but are mostly AIDS orientated.

We have no national or state HCV community based organisations although there are a some prevention type agencies (Mainliners) and support group type websites.

We do have access to PCR testing but just the viral detection test only. Our hep C treatments include interferon, ribavirin and amantadine.

There are restrictions on treatment and it depends where you live. Health Authorities won't pay for it in most places.

In regard to support or promotion of alternative therapies for hep C, it doesn't happen here in the UK.

I haven't yet come across hep C related discrimination or stigmatisation, but it's there waiting I'm sure.

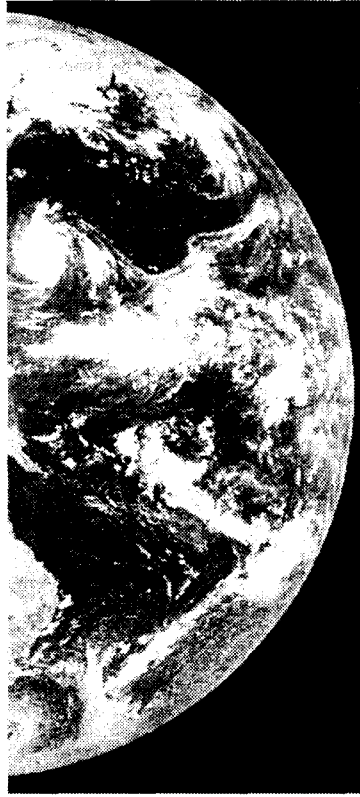
Hepatitis C is still treated as a mild disease by the UK National Health Service.

A personal view from Israel

Sorry about the limitations of my response but here in Israel, there is silence on hepatitis C. Our government is sweeping it under the table.

I'm not aware of any HCV transmission prevention strategies, nor do we have any national or local hepatitis C organisations.

Although we do have access to PCR testing, I'm not sure if there are any limitations.



Interferon is available in Israel for hep C and perhaps, the combo therapy as well.

Here in Israel, natural therapies are not generally promoted. Alternative medicine is private.

In regard to your question about people with hepatitis C experiencing discrimination, I'm not sure. Most people in Israel don't know what it is.

A personal view from Canada.

In the event you have not heard from anyone here I will offer what information I can.

Our government doesn't have a coordinated HCV strategy but the outcroppings of groups such as Laboratory Centre for Disease Control, Workers Compensation Board and others are starting to emerge.

There are no HCV transmission prevention initiatives in Canada.

We have several national HCV community based organisations: the National Hepatitis C Society of Canada (hecsc@idirect.com), the Canadian Liver Foundation and Canadian Haemophilia Society.

My local provincial organisation is British Columbia Hepatitis Foundation (bchepc@bc.sympatico.ca).

Only people involved in clinical trials or research have any free access to PCR testing. It is simply not available, nor do most know about these tests here in Canada.

In Canada, hep C treatments include interferon and the interferon / ribavirin combination therapy. The current restrictions on combo treatment are age (not under 19 or over 60), heart condition (known heart problems cannot participate) and state of mind (people depressed cannot participate).

There is no support or promotion of alternative therapies for hep C here in Canada.

In regard to hep C related discrimination or stigmatisation, yes, people here most definitely have problems with their HCV. Although it is illegal to discriminate, a person with HCV would have to prove the HCV discrimination - which can be difficult depending on whether the discrimination is indirect or masked.

Additionally, here in Canada there is a severe lack of independent research funding (not involving the drug companies). Also there is a lack of recognition about the seriousness of the disease and the extent to which it affects the population (400,000 Canadians have HCV). Further there is a failure to educate doctors as to the lifestyle advice and treatment appropriate to HCV infected.

A personal view from Indonesia

It is estimated that there are about 5 million people in Indonesia who are chronically infected with the hepatitis C virus and 10 million chronically infected with hepatitis B. The total population of Indonesia is approximately 190 million. As at December 1994, donated blood was still not being screened by the Indonesian Red Cross Blood Transfusion Unit for the presence of the hepatitis C virus because of the inability of the unit to meet the cost.

Despite these depressing facts, there is some hepatitis-C-related research being conducted in Indonesia which, it is hoped, will lead to the introduction of screening of blood for HCV in Indonesia.

On the island of Lombok in the Indonesian province of Nusa Tenggara Barat (NTB), there is a hepatitis C research institute which has been developing a reagent now known as the "Entebe (NTB) Dipstick"; a name derived from the initials of the Province. A comb made from polystyrene and containing CP-9 and CP-14 (core proteins) and gold chloride is dipped into a blood sample to detect anti-HCV.

With such an overwhelming incidence of HCV, it is unlikely that the Indonesian people will have access to government-funded trials of interferon for the treatment of chronic HCV.

Kompas, 4 March 1996 and 8 February 1995

- From information provided by a Council member, recently returned from working in Indonesia.

Hepatitis C in NSW, Australia

Latest news from NSW has been the release of the report, *Hepatitis C: The Neglected Epidemic* produced by the NSW Parliamentary Standing Committee into Social Issues.

Committee Chair, Jan Burnswoods, said that the evidence taken and submissions received from people with HCV portrayed the the stark realities of the disease: the overwhelming and debilitating fatigue; the fear of transmitting the virus to others; uncertainties over the future; and failing health.

The Committee found there is no overarching policy to guide and direct the control, treatment and prevention of hepatitis C.

Ms Burnswoods said that the Committee members had unanimously proposed a framework for the state to respond appropriately and adequately to this disease.

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What do US hep C activists say about 'bundling'?

Ribavirin is currently 'bundled' with Schering-Plough's Intron A. Following are position statements from the US based HCV activist group, HEP C ALERT.

HINDERING OF PHYSICIANS' ABILITY TO PRESCRIBE OFF-LABEL

The bundling prevents doctors from prescribing ribavirin appropriately in combination with other versions of interferon on the market. Some patients respond better and/or experience fewer adverse reactions to one over the other. Bundling limits the physician's ability to making dosing adjustments of both the ribavirin and the interferon.

ALTERNATIVE ACCESS

Many patients are obtaining the drug from Mexico via buyer's clubs at one third of the price of the Schering US product. These buyer's clubs report that they get about 50% of the insurance companies to pay for the Mexican product when with provided a letter from the prescribing physician. They see the cost savings.

The biggest danger here though is that people are getting a product with no warnings, or medication guide on how to use the product. Some people are getting unlabelled ribavirin from labs in England. This is clearly getting more risky.

Most risky of all, is that we are aware of at least two underground labs in the US getting ready to manufacture ribavirin and sell it at a quarter of Schering's price. Something is clearly wrong in the market when patients are resorting to bathtub versions of drug.

IMPEDING RESEARCH

Bundling has slowed the ability of researchers to test ribavirin with other interferons. Schering does not make ribavirin readily available to researchers from other companies to test. They claim that ribavirin has only been tested with their product, therefore it is the only one with which it should be combined. Yet, they conducted no studies to compare the efficacy of ribavirin with other interferons. Schering's marketing practices have insured that this will be very difficult to do.

Some researchers we have spoken with are seriously considering obtaining ribavirin from sources outside the US. They seem to feel it is equivalent. It is still available separately and at one third the US price in other countries. We cannot expect other researchers to purchase bundled product and waste the Intron A. Roche has gone so far as to develop its own version of ribavirin to test. This situation is needlessly adding to the cost of research and will end up being borne out in continued upward spiralling of retail pricing of these drugs. It further erodes inter-company cooperation in research.

PRECEDENT FOR FUTURE PRODUCTS

Bundling sets a dangerous precedent. Any future permutations of combination therapies that come along for HCV, or other diseases, will be expected by the pharmaceutical industry to be allowed to be bundled.

We can expect more usage patents, higher costs, and impeded research. This situation could create a bureaucratic nightmare for the FDA. It is a strategy geared for short term gain by Schering and long-term loss for everyone.

PRICING

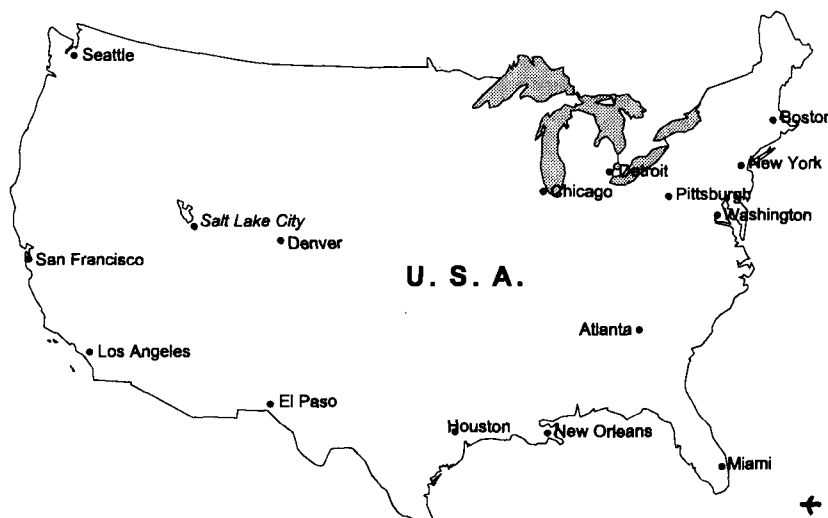
Ribavirin is currently priced 357% above the next highest priced drug in the same nucleoside analogue antiviral class (AZT).

Ribavirin should be cut in price by 75% from the current estimated price of \$1020/month (1200 mg/day dosing) to \$255/month, which is nearer its 1995 price and more in line with current drugs in its class.

Schering has ample opportunity to continue to make substantial profits with a lower priced, unbundled ribavirin product as it is in demand to be used with interferons from other companies.

- Abridged from a HEP C ALERT press release, downloaded from the internet email site, HEPV-L.

[The above information relates to the United States. It is provided for your interest in the context of an 'overseas update'. Also see news item, pg. 12 ... Ed]



Conference buzz

The 5th HIV/AIDS and Society Conference was recently held at Macquarie University, Sydney. In most streams there were sessions that related to IDU leading to much discussion on hepatitis C.

Many attendees were distressed about a recent press release from the NSW Minister for Health on removal of large bore syringes from needle and syringe outlets. Trumpeted by the minister as an 'initiative' aimed at preventing people injecting methadone, many who spoke believed the development would lead to increased transmission of HCV.

Findings of a recent survey, presented by Tony Rance and Tamaris Cameron from NUAA, suggested that people who currently inject methadone will continue to inject the medication even if it is difficult to obtain suitable needles. The survey findings suggests that as a consequence, people will resort to cleaning, reusing and sharing already used needles. It was noted that cleaning of methadone injecting equipment is near impossible (especially butterfly needles). Because many people who inject methadone are hepatitis C positive it is exceedingly likely that HCV incidence will increase.

Jan Cregan, a social researcher at the National Centre in HIV Social Research, Macquarie University, discussed Tony Butler's 1997 findings that 33% of males and 66% of females entering NSW gaols are hepatitis C positive. Her own research showed that 65% of prisoners gaoled for drug related offences report injecting while in prison and that up to 80% of these people are estimated to be hepatitis C positive.

As clean needles and other injecting equipment are not distributed within gaols, many prisoners share injecting equipment. Consequently, prisoners who inject are extremely likely to contract HCV and/or become reinfected with different subtypes of HCV.

Jan also discussed the place of the term 'community' in targeting hepatitis C prevention and treatment programs. In relation to prevention, as HCV incidence rates are highest among young injectors, hepatitis C information and prevention must be targeted at young people beginning to use drugs or making the transition to injecting (possibly including school-based programs).

In relation to treatment, as hepatitis C symptoms tend to emerge 10-15 years after infection, many people needing access to treatment and support services will no longer inject drugs or identify with programs targeted at a drug using community. Nor will those who have contracted hepatitis C through routes other than injecting. By comparison with the gay community partnership approach to HIV/AIDS, which is effective for both education/prevention and treatment/support, the situation in relation to hepatitis C is more complex with the boundaries of drug user and hepatitis C communities blurring into notions of 'general community' for early prevention and treatment programs.

Swiss HCV transmission reduced

A decrease in the incidence and prevalence of hepatitis C infection has occurred among drug users in Geneva on methadone maintenance during the past 8 years. The decline suggests that people who inject drugs have changed injecting behaviour in response to Swiss HIV prevention campaigns.

Dr. Bernard Hirschel and colleagues at the University Hospital in Geneva conducted a study of 706 drug users participating in a private methadone maintenance treatment program between 1988 and 1995. All had hepatitis C tests twice a year, along with HIV and hepatitis B tests.

The study noted dramatic decreases in the prevalence of all three viruses over time. The prevalence of HCV among people who entered treatment before 1988 was 91.6% compared to 29.8% among people who entered treatment after 1993. Similarly, the prevalence of HBV and HIV declined from 80.5% to 20.1%, and 38.2% to 4.5%, respectively, during the same time period.

Annual incidence rates per person-year of follow-up for HCV were relatively high (4.2%) - particularly high among women (9.6%) - in comparison to HIV (0.6%) and HBV (2.1%) the study reported.

In addition to the national HIV information campaigns that began after 1986, several other HIV prevention measures were instituted in Geneva. In 1987, fets became available through pharmacies and, in 1991, needle exchange programs were initiated. Methadone treatment programs also became increasingly available during this period.

Overall, the findings suggest to Dr. Hirschel's group that HIV prevention campaigns are working, but that more emphasis on HCV prevention is needed. The researchers therefore suggested that "...public health intervention should shift to a combined focus on hepatitis and HIV."

- Abridged from a press release, downloaded from the internet email site, HEPV-L.

Nick Crofts presented a paper which highlighted findings on the impact of hepatitis C infection on people's quality of life. The research involved hepatitis C antibody tests on stored blood samples gathered from people with acute hepatitis in Fairfield Infectious Diseases Hospital between 1971 and 1975.

It was found that people who were HCV+ but had not been aware of their positive status had no difference in 'quality of life' (assessed by the SF-36 Scale) to people who were HCV negative. It suggested that only people who were actually aware of their HCV infection had a poorer 'quality of life' scale score. One may think that the HCV+ people who were aware of their status, were so because they had been symptomatic and due to their symptoms had a poorer 'quality of life'. However, there was no link found between 'quality of life' scores and presence of symptoms.

These results may be due to the effects of 'labelling' or through having no pre- or post-test counselling. The implications of this study are not clear.

Overall, it was great to see so much focus on hepatitis C social research within an HIV conference.

- Jenny Melrose is a member of our Editorial Committee, a Council Management Committee member and an intern Psychologist at Foley House, Surry Hills, Sydney.



Unhealthy state of romance

By Ruth Ostrow

As often happens to me, a guy I met at a party decided to use me as a confessional booth.

Having been single and celibate for quite some time, he had recently met a fantastic woman. She was exciting, challenging, and very sexually attractive.

Although she liked him very much, she refused to kiss him. This went on for weeks.

Her reasoning was that with the rash of superbugs and viruses out there, she didn't want to take a risk.

At one of their romantic dinners, she pointed out that at least one of the new hepatitis strains could be transmitted orally. Furthermore, she claimed the first case of mouth-to-mouth HIV had been recorded in the US.

She explained that she wanted to kiss him very much, but needed to spend time "getting to know him". Which, in 1990s lingo, means hygienic interrogation - a state of pre-love stasis where the datee asks the dater innocuous questions like: "Were you in Africa recently? Did you tongue-kiss any Ebola victims?"

He was mortified, but because of his already prolonged state of deprivation, decided to be patient a little longer and assuage all her concerns as they came up.

Finally, miraculously, they found themselves in a passionate embrace one night, and all went well. Until the next hurdle.

As they started getting down to business, she asked that the light be left on. He found this a bit unusual, as most women, in his experience, were initially very shy about their bodies.

Figuring she must be a bit kinky, he got stuck into it - only to realise her motivation wasn't sexual. Every time he looked up to gaze into her eyes, she was inspecting some bump or lump on his body, her hands running up and down his anatomy like some medical scanner.

I wasn't being caressed, I was being diagnosed!" he moaned. And, as the old saying goes: "Seek and ye shall find".

She had noticed a dark mark on his private part. A freckle, he assured her, that had always been there.

Always? she queried, shaking her head. How long? Since he was a child? An adolescent? Had a doctor ever examined it? All while turning the aforementioned part this way and that.

While she humiliated him with the third-degree, she kept scrutinising the tiny freckle under her microscopic glare and giving him a blow-by-blow analysis of the dreaded wart virus.

Finally, she declared an act of consummation between them was impossible until he had taken his freckle to the doctor.

He never went to the doctor, and he never rang her again. He got to the point where the whole thing just turned him off.

"I believe in safe sex, but you've got to draw the line somewhere," he said. I had to agree.

And while I'm a big supporter of safer-than-safe sex, I have discovered in my travels a creature, very much a product of the 1990s, who takes fear too far: The Sexual Hypochondriac.

"Sexual, hypochondriacs have always been around, resisting orgies in the '70s for fear of getting crook necks, never sitting on toilets in the '80s for fear of picking up something or somebody, always terrified that they are, or have got someone, pregnant - riddled with neuroses about their bodies, health and mortality.

Now, in this era of extreme (if justifiable) health paranoia, they're out with a vengeance. Their catch-cry is "Sex can kill!"

And while we now know, tragically, that it can, so can driving cars, crossing the road, or air travel. The art of living well is knowing where to draw the line, and when to take calculated risks.

There has to be some mystery, joy, love and spontaneity left in the mating game. And when your date regards you more as a pathology than a person, is more interested in your medical records than your soul, then - as this poor fellow-concluded - it's time to split.

- Ruth Ostrow is a relationship journalist who writes a regular column in the *Sunday Telegraph*.

[Community-wide awareness campaigns will help dispel the myth that hepatitis C is sexually transmitted. We've printed this article because so many people falsely believe it is and this can have such an affect on people's current or future relationships.]

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	<p>Group 1: interferon @ 10mu daily for 4 wks, then 5mu 3x weekly for 48 wks. Ribavirin given twice daily.</p> <p>Group 2: interferon @ 10mu daily for 4 wks, then 5mu 3x weekly for 48 wks. Placebo capsules given twice daily.</p>	<p>Group 1: interferon @ 9mu daily for 1 mth, then 3mu 3x weekly for > 1 year.</p> <p>Group 2: interferon @ 6mu daily for 1 mth, then 3mu 3x weekly for > 1 year.</p> <p>Group 3: interferon @ 3mu 3x weekly for > 1 year.</p>	<p>(Genotypes 1 or 4)</p> <p>Group 1: interferon @ 5mu daily for 8 wks, then 3mu 3x wkly for 44 weeks; plus ribavirin, daily for 52 wks.</p> <p>Group 2: interferon @ 3mu 3x wkly for 52 wks; plus ribavirin, daily for 52 wks.</p> <p>(Genotypes 2 or 3)</p> <p>Group 1: interferon @ 3mu daily for 4 wks, then 3mu 3x wkly for 20 wks; plus ribavirin, daily for 24 wks.</p> <p>Group 2: interferon @ 3mu 3x wkly for 24 wks; plus ribavirin, daily for 24 wks.</p>	<p>Participants will not know whether they are taking CH100 or placebo.</p> <p>GP visits and health status surveys at 0,1,3,6,9 mnths.</p> <p>LFTs at 0,1,3,6,9 mnths.</p> <p>PCR genotyping at beginning of trial.</p> <p>PCR viral detection and viral load tests at beginning and at 24 wks.</p> <p>Group 1: CH100 taken 3x daily for 24 wks.</p> <p>Group 2: Placebo (harmless substitute) taken 3x daily for 24 wks.</p>
Where are treatment centres?	Not applicable as enrolments closed.	Nepean, Wollongong, Concord, St Vincents, 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 mnths 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.	Yes. Contact the liver clinic at your nearest trial centre. See above.	Enrolment will be open soon but because specific trial centres haven't been finalised. 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).

Hepatitis through the ages

A series of articles that explain 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

Realising the problem

Doctors have known about hepatitis, a condition that causes the skin to turn yellow, since ancient times. Over the past twenty-two centuries, epidemics were occasionally noted in civilians, but hepatitis most often occurred under wartime conditions.

Napoleon's armies were hit with an outbreak; both armies of the American Civil War were struck hard; and hepatitis helped change the course of several battles during World War I. But no one knew what caused hepatitis, and it wasn't until World War II that doctors found out it could be transmitted from one person to another through blood.

During World War II there were 200,000 documented cases of hepatitis among US soldiers; 352 died. Five million Germans are said to have contracted the disease, as well. The epidemic caught everyone by surprise, but health officials quickly figured out what must have caused the illness in the United States soldiers.

In 1942 seven million doses of a new yellow fever vaccine were sent to the US Army. Health officials were trying to prevent an epidemic of this disease, which sometimes strikes under wartime conditions.

The vaccine prevented the yellow fever, but many soldiers came down with "yellow jaundice" (a name often used for hepatitis because of the yellowish tint it gives the eyes).

It turns out that the vaccine had been prepared using blood serum contaminated with a virus that causes hepatitis. But no one knew that at the time because there were no tests available to detect such viruses.

This epidemic changed the way hepatitis was perceived by the world. After World War II, hepatitis was no longer thought of as just a disease of overcrowded and unsanitary conditions. If it

could be transmitted in a vaccine, then anyone could get it, through blood transfusions or other exposure to blood.

The first pieces of the puzzle:

In the mid-1950s Saul Krugman, a professor at New York University Medical School, was contacted by the Willowbrook State School for Disabled Children in Staten Island.

Hepatitis was epidemic at the institute, and the hospital officials wondered if Dr Krugman could help. In just a few years, the NYU researcher helped end the Willowbrook epidemic. At the same time he discovered many things about hepatitis, which eventually led to a vaccine that has prevented millions from getting the disease. However, his efforts also resulted in bitter controversy.

Because no one knew what caused hepatitis, Dr Krugman was faced with a difficult task in trying to eliminate it.

Many clinicians believed a virus was responsible yet in the 1950s there were no antiviral drugs available - even today there are not many effective treatments for viral diseases.

Prevention is the key to controlling viral diseases. Usually that means using a vaccine. But in order to produce a vaccine, one has to find the virus that the vaccine is supposed to work against.

Dr Krugman's experiments began in 1956 and lasted for seven years. "It was inevitable that all newly admitted children would come down with hepatitis; they couldn't escape it. So he realised that the only way he could learn something about the disease which would eventually lead to prevention was by studying small groups of children and actually exposing them to the same Willowbrook strain of hepatitis that they were going to live with anyway as soon as they came into the institution," Saul Krugman later explained, after news of his experiments sparked a hotly debated controversy.

When the body is exposed to viruses, it builds special proteins called antibodies, which are custom-designed to attack that particular type of virus. The next time the body encounters that kind of virus, the antibodies spring into action, preventing the person from becoming infected again. (In medical terms he or she is immune to that viral disease.)

Dr Krugman showed that injecting antibodies that other people had built up against hepatitis gave temporary protection to those who had not yet been exposed to the virus.

Dr Krugman also showed that once a person got hepatitis, he or she was immune. But then something surprising happened. Some of the children who had got the disease suffered a second attack within a year. The NYU researcher wondered whether the second attack could be due to a different virus. Hepatitis had traditionally been associated with overcrowded, unsanitary conditions. But the soldiers in World War II had got the disease from contaminated vaccines. Could there be two different diseases with similar symptoms?

This article will be continued in our next editions. It eventually explains the history of HCV and other hepatitis viruses.

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Do you think you might have hepatitis C?



To find out more
about hepatitis C

call the
NSW Hep C Info
& Support Service

9332 1599
for Sydney callers

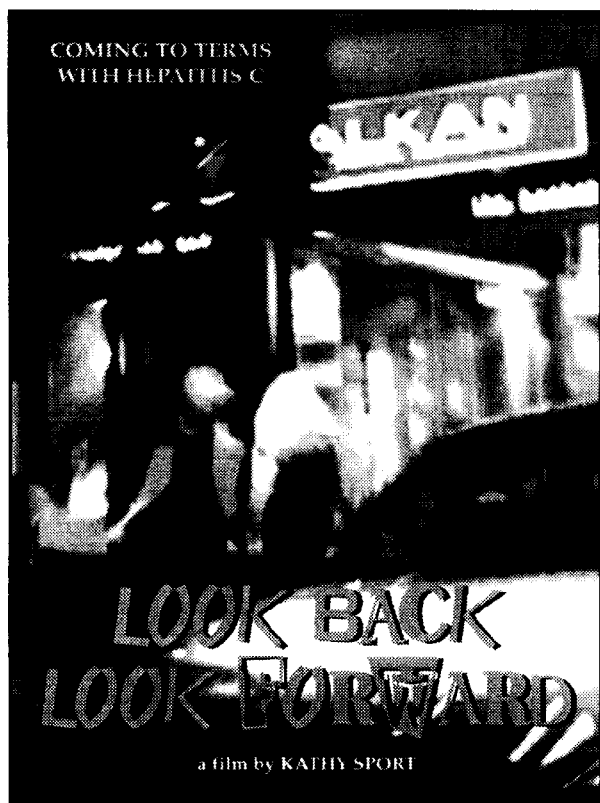
1800 803 990
for NSW callers

Complementary therapies and treatments

What has been your experience of complementary therapies?

Are they effective? Can they work hand-in-hand with western medicine? Are they over-priced? Do they require more regulation?

Please write in with your views and comments, and also let us know if you have particular questions you'd like answered.



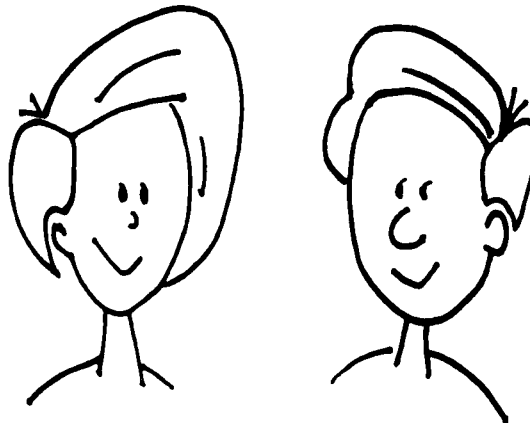
The new video
LOOK BACK LOOK FORWARD
is available for loan.

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

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

Hey, I just moved from Queensland and my new GP is sending my 3 year follow up report

I stopped interferon treatment after 3 months but I still attend for regular check-ups



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



healthy
&
happy

Within SPAN, the Hepatitis C Council has a web page at:
http://www.span.com.au/hepatitis_c/info.html

Our site contains general information taken from
Hepatitis C: what you need to know.

The Comedy Hotel
Is The Harold Park Hotel

115 Wigram Road
Glebe NSW 2037

Tel: 9552 1791



Our thanks to the Comedy Hotel,
Glebe, for their kind support of
our dedicated mailout volunteers.

**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 page 16) 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 (see page 16) 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*, and phone the NSW Hepatitis C Telephone Information & Support Service on 1800 803 990 (NSW callers) or 9332 1599 (Sydney callers).

Benefits

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

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



Complementary therapies

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

Certainly though, many people report positive benefits.

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

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

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

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

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

Costs

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

Choosing a practitioner

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

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

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

Healthy herbs?

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

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

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

Want more information?

Contact any of the following organisations:

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

NSW Hep C Telephone Info and Support Service

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

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

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

Sexual health clinics

Although hepatitis C is not classified as a sexually transmitted disease, staff at these clinics can offer a range of services including pre- and post-test counselling, antibody blood tests, general counselling and primary healthcare (the type of service that GPs provide).

They are listed in your local phone book under 'sexual health clinics'. If you are concerned about confidentiality, these clinics do not need your surname and keep all medical records strictly 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	Chris Bourne	02 6882 9858
Hunter	Marilyn Bliss	02 4924 6477
Mid West NSW	Dave Brackenreg	02 6332 8576
Southern NSW	Geetha Isaac-Toua	02 4827 3413
South West NSW	Dalton Dupuy	02 6058 1700
Nthn Rivers	Wendi Evans	02 6620 7505
	Linda Blackmore	02 6688 2088
New England	Karin Ficher	02 6766 2288
Central Coast	Karen Nairn	02 4320 3399
Illawarra	Brian O'Neill	02 4228 8211
Wentworth area	Elizabeth O'Neill	02 4724 3877
Western Sydney	Chris O'Reilly	9840 4105
	Rob Wilkins	9840 4110
Nthn Sydney	Bernie Coates	9926 6717
Central Sydney	Peter Todaro	9515 9600
	Jan Pritchard-Jones	9515 8643
Far West NSW	Darriea Turley	08 8080 1511
SE Sydney	David Willock	9382 8370
Sth Wst Sydney	Ken Wong	9827 8033
	Laura Baird	99828 5944

One-to-one counselling

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

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

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

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

Family counselling

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

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



regular feature - hcv information

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.

Description

- 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

Description

- Hepatitis C - a brief introduction** - (brochure @ \$5 per 100)
- Hepatitis C - what you need to know** - (booklet)
- Video 1 - Interferon / HCV & women** - (you pay return postage)
- Video 2 - homoeopathy / herbalism** - (you pay return postage)
- Video 4 - hepatitis C / the liver** - (you pay return postage)
- Look Back Look Forward** - coming to terms with hepatitis C
- 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

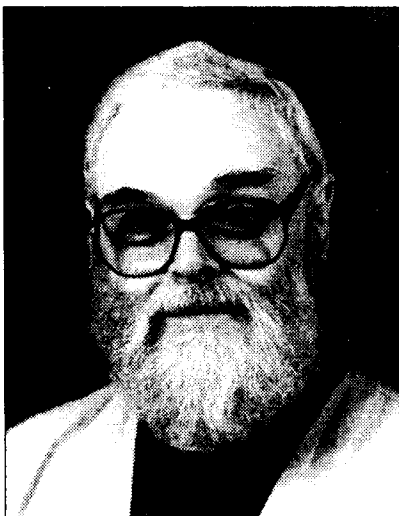
We have an abridged version of our booklet on our website. Look for it at .. http://www.span.com.au/hepatitis_c/info.html

Hepatitis C Council of NSW - 1998/99 AGM

Our Sept. 10 Annual General Meeting was very much a success, with a good turn out of members.

Following reports on the Council's work over the 1997/98 financial year, life membership was awarded to Margaret Harvey of Wyong in recognition of her ongoing and committed volunteer involvement.

Our new 1998/99 management committee was formed, with the nine nominations received, elected unopposed. MC members are: Cheryl Burman (President), Jennifer Holmes (Vice President), Don Griffin (Secretary), Robert Tinsey (Treasurer), Jan Cregan, Bernard Fisher, Neshko Garch, Anita Long, Stuart Loveday, Jenny Melrose, Therese Reeves, Allison Salmon and Peter Todaro.



The sad loss of an old friend

Rev Harold Smart, 14/11/40 to 2/10/98

We would like to remember and thank Harold Smart, Life Member of the Hepatitis C Council of NSW. We feel sadness, because we have all lost, in Harold, a great friend, healer, humanist, activist and source of inspiration. We feel hope and thanks because we all saw and benefited from his great inner strength and love which crossed all boundaries: without judgement, fear or bitterness; without a selfish thought.

Harold was a tireless campaigner for the rights and health of all people affected by hepatitis C and he insisted that decision makers and power holders focus their attention and resources on preventing harm and improving quality of life.

Thank you, Harold.

