HEPATITIS C COUNCIL OF NSW

Newsletter Backcopies - Editions 1-9

Preface - A Brief History

The identification of the hepatitis C virus (HCV) in 1988 established a new era in the scientific understanding of hepatitis C, previously known as Non-A/Non-B hepatitis. In stark contrast though, individual people affected still faced confusion and ignorance regarding their condition. A need for community-wide information and support was and remains clearly visible. **Professor Geoffrey Farrell** of Westmead Hospital recognised this need. He supported the setting-up of a patient support group that inaugurated in November 1991 as the NSW Hepatitis C Support Group. The primary purpose of this group was to provide support for people with HCV, and to represent the interests of such people within the broader community. A toll-free 008 support line involving a network of metropolitan and non-metropolitan volunteer telephone counsellors was established.

The group became incorporated in February 1993, as the **Australian Hepatitis C Support Group**, soon gaining the status of a registered charity. While remaining committed to client support services, the group increasingly began to address public and peer education. The focus of the organisation had begun to include Federal issues as well, such as access to Interferon treatment and social security pensions. Liaison with peer health and welfare based agencies had also increased considerably.

With federal funding submissions rejected, the group could not function on a national level, and in July 1994, the Australian Hepatitis C Support Group reformed as **The Hepatitis C Council of NSW**, moving to its first offices at Belmore St, Surry Hills in Sydney.

1994 also marked the **NSW Health Department's** formal acknowledgment of the Hepatitis C Council's role by providing ongoing funding for the provision of counselling and support services. This marked the beginning of a shared commitment to address HCV need within the NSW community.

In October 1994, NSW Health convened a state **HCV Taskforce**, aimed at identifying gaps in HCV healthcare provision, and proposing strategies that would meet such gaps. The Hepatitis C Council was invited to sit on this taskforce along with other community-based groups and government departments.

In December 1994, we relocated to more suitable office accommodation at Crown St, Surry Hills. In February 1995, NSW Health approved further funding as a contribution to our core operating costs. This has enabled us to provide a more professional and effective service.

Australian Hepatitis C Support Group Inc.

PO Box 98 Westmead, NSW 2145

Fax (02) 584 9194
Support Line: 008 803 990

Newsletter No. 4 May 1993

Hepatitis C Update Seminar

Synopsis of proceedings Curtin University of Technology Bentley, Western Australia 17 February 1993

INTRODUCTION AND OVERVIEW

Associate Professor Bill Saunders, *Addiction Studies Unit, School of Psychology, Curtin University of Technology.*

In the introduction two aspects were emphasised. First, HIV became an issue in Australia largely from lobbying, discussions, seminars, and generally pushing the debate along. It did not occur by research alone. The successful response was not by accident "it had to be made to happen".

Secondly, while from within Australia our response to drug problems may not appear too exciting (eg the Tobacco Control Act, methadone provision, as needle exchanges etc) when considered by overseas authorities Australia is seen as performing very well. However, Australia's response to HCV was not yet distinguished by ingenuity, priority, or allocation of adequate resources.

The chairman noted, however, that he hoped that the seminar would/will encourage common cause to be made and priorities to be set.

TOPIC 1 WHAT WE KNOW SO FAR – THE NATURAL HISTORY OF HCV

Dr Bill Reed, *Department of Medicine, University of Western Australia.*

Current knowledge of the composition of the HCV, histology, immunopathology, international distribution of HCV, clinical features and methods of diagnosis were described. In particular, the importance of HCV PCR was discussed and caution with its use was recommended due its sensitivity as a test. The main point to emerge from discussion of treatment was that those with mild disease are more likely to respond well.

The following factors affecting the likelihood of developing serious disease from Hep C were listed: age, duration of infection, aetiology, histology when detected, viral load, viral strain and alcohol use.

TOPIC 2 MANAGEMENT AND EPIDEMIOLOGY

Dr Katrinia Watson, *St Vincent's Hospital, Victoria*

The need for Australian epidemiological data was highlighted. Studies pointing to higher risk in groups such as male homosexuals, female sex industry workers and people with more than one lifetime sex partner were discussed, but it was noted that the statistical effect of such groups being IVDUs had not been identified. Other high risk groups were identified as: multiple transfusion recipients, haemophiliacs, dialysis patients, transplant patients, health care workers, IVDUs, sexual/household contacts.

Age and ethnicity were related to the three major HCV groups ie IVDUs, transfusion and sporadic infections. The main transmission types were classified (blood products, needle sharing, sexual contact and household) and discussed. The question of why in needle stick incidents HCV appears to be transmitted so much more efficiently than HIV was raised.

Again, caution was recommended in the interpretation of PCR results and reports based on PCR results.

The effectiveness of current alpha interferon treatment was described in relation to relapse and remission, stages of the disease at which it was used, gender, histology, side effects, and psychological implications.

The likelihood of an at least 10 year period before vaccine becomes widely available was used to support treatment, and other preventives, as a very important public health goal.

continued page 3

NEWS

FROM THE BRANCHES

VICTORIA A very successful meeting was held in May and the numbers of members now are over the 30 mark. Other get togethers are planned. The President (Joan) and Secretary (Sharon) will welcome any help and can be reached via the new answering machine at Joan's. The phone number there is (03) 773 1362, and the postal address for Victoria is P.O. Box 211, Bentleigh 3204. Joan would be delighted to hear of a bookkeeper to keep the accounts, people to man phones and anyone who has contacts with the media and can help. This newsletter is set out in Melbourne, and I am sure you agree that it is a great presentation.

TASMANIA We now have another phone contact in Tasmania – this time in the south of the state. His name is Phil at (002) 865 156. The enquiries from Tassie are slowly starting to trickle in.

SOUTH AUSTRALIA Another state from which we have had few enquiries in the past, but it looks as if it could be changing soon.

WEST AUSTRALIA Business is booming over in the west with over 70 members. They are very pleased to at last in February have had Hepatitis C made a notifiable disease, so that reasonably accurate statistics can be kept. Their annual meeting is to be held 14th June and the contacts there are Ali (09 370 1901) or Liz (09 272 1305). The postal address is P.O. Box 266, Inglewood 6052. Research is being conducted in WA to determine whether HCV is present in breast milk.

QUEENSLAND There is a member in Cairns who is keen to start a support group, but no other members near her. We had two enquiries from professionals in Rockhampton saying that they were interested in setting up a support group, but as yet they have not joined us as members. Stephen is still holding the fort for any local phone support (071 281 373 evenings), but Wendy should be back in July/August.

continued page 2

NEWS continued

Hopefully there will be a group on the Gold Coast we can report on in the next newsletter. In that area contact Karen L'Arbalestier on (075) 769 033.

NEW SOUTH WALES Things have been busy in this state too. There has been a lot of push to try and get Interferon accepted on to the Pharmaceutical Benefits Schedule so there was some publicity in the Sunday Telegraph and also on Channel 7 main news, with SBS coming up. There was an excellent Quantum programme on ABC on the liver, some explanation being given by Professor Farrell. We have been very busy with sending out the petition to state members, to be presented to Parliament before 20th May. April saw a wonderful meeting with Professor Farrell staying and answering every question that the audience could come up with. On June 9th at 7pm at Westmead, in Lecture Theatre 1, Dr. Weltman will answer questions on Cirrhosis.

We have also written again to the Minister for Health in this state requesting an interview, asking for a Project Officer to coordinate all activities for Hepatitis C and counsellors educated in the disease to be provided in each area, but as yet have had no acknowledgement.

The **Central Coast Group** is going well with interesting meetings every couple of months and good friendship developing. The next meeting will be on June 23rd at 7.30 pm when Kate Baker will speak on "Stress and Relaxation". Enquiries ring Heather on (043) 26 1186 (day).

An excellent meeting was held in **Newcastle** recently with approximately 90 persons attending. A committee will be formed shortly and excellent work is being done by Leone (049 47 1206) who is receiving some support from local health authorities, especially Professor Bob Batey of John Hunter Hospital.

At **Lismore** on the north coast, my apologies to Fiona who had not wanted her phone number published as she is only there one day per week. The phone contact now is Robyn (066 222 108). A group should soon be formed there. Coff's Harbour is also making moves for a group. South Coast of NSW is another interested area and we have a lady at Bowral who would like to contact with others in the area. If you are interested in any of these moves, Audrey can put you in contact with the relevant people.

Central Executive On a Federal scale, we are delighted to have it confirmed that our insurance (and therefore incorporation) stands up in all states. However, the Chief Secretary's Department has lost our application for registration as a Charitable Institution!

We are in the process of working out the feasibility of putting in two submissions to Canberra for funding of projects under the Community Organisations Support Programme, and they have to be in by the end of May. One is for the setting up of a national information base on HCV which can be accessed by both medical practitioners and the public, and the other is for a pilot study to be done in Victoria to determine the needs of HCV sufferers.

There is planning underway for a workshop/conference for professionals to be held in Sydney in November of this year, which we hope will attract a high level of participants as we are trying to have major researchers present. We should have some results of the Australian trials of Interferon after September of this year.

There is rejoicing in the fact that at last our phone counsellors have received some formal training. We had a full day of the theory behind what we are supposed to do, and some notes are now available. We hope to persuade the relevant authorities to provide another half day of "hands on" training, during which we can practice the updated information which is now available to all phone counsellors. If you feel you have missed out, please contact Audrey (02 584 2421).

You will find enclosed with this Newsletter a letter to the Minister for Health in the Federal government, asking for coordinated action to be taken about HCV. Please give this letter your attention and get as many as we can to Senator Richardson. This appears to be the only way we may get a little more attention paid to our needs. The federal Health Department advises that there is a to be a working party report in July, targeted particularly toward the issues of Interferon treatment for HCV.

How we spend your money

For each Group member, $8 per year goes on the production and posting of the four newsletters you get. Approximately $1.30 goes on mailing of things like petitions, notices. The rest is spent on the phone bill ($250.00 per month) postage, (particularly sending out information at the request of the 008 callers) photocopying supplies and stationery. (The photocopier eats a lot – each 1,500 sheets is another $10 for toner, and at 20,000 there is the cost of a new drum which is $400. In the three months we have had it, we have copied nearly 6,000 sheets.) We also carry some persons who have no income at all as well as those whom it is deemed politically wise to keep informed of what we are doing.

Of all the people who ring in, less than 10% join the group – let's face it, many people want something for nothing, and once their anxiety is allayed, they do not think what we are offering is valuable. Most Group members are on pensions and so pay the concessional rate.

We have been given (by an anonymous donor) the fax, answering machine and photocopier, and also a little funding for a part time secretary to keep up the data base of members, put some order into the filing and make some of the phone calls.

Taurine protects the liver

New Scientist on the latest findings of researchers at the School of pharmacy in London (New Scientist 3.4.93 "Why Breast is Best for Liver") that in rats, at least, an amino acid called taurine, protects the liver and helps it to deal with toxic substances. The researchers found that when rats had a taurine deficiency, their susceptibility to liver damage from poisons increased. When the animals were exposed to a variety of poisons, those with the lowest level of taurine in their livers, sustained the greatest liver damage. Natural levels of taurine in rats also increased dramatically when the rats were exposed to the chemicals, and this increase matched the extent of the damage.

Rats make taurine more efficiently than humans and the researchers concluded that humans may therefore be at more risk from toxic chemicals than rats. New Scientist notes that "strict vegetarians who eat no animal products of any kind and so take in little taurine may be particularly at risk."

For those who suffer from chronic active hepatitis C and whose lives are already compromised by the infection, it is clear that toxic chemical exposure must be avoided at all times. It would also seem wise to avoid an animal product-less diet unless there are other health related reasons. Taurine is found in human's milk but not in cow's milk so it is added to baby formulations which are based on cow's milk.

Precis by Warren 1 May 1993

TOPIC 3 THE WEST AUSTRALIAN ALCOHOL AND DRUG AUTHORITY

Dr Richard Saker, *Senior Medical Officer, West Australian Alcohol and Drug Authority.*

A brief description of the prevalence of IVDU in various groups in WA was given. It was estimated that 15-30,000 people in WA have ever injected, 2-5,000 are currently injecting, 1-2,000 are injecting regularly, and 500 are currently on a methadone program. Of this latter group, 90% are antibody positive; are in their 30s, have injected for approximately 6-7 years, and have been treated for around 2 years. Particular issues with amphetamine injectors were raised, including: prevalence which is unknown, but numbers of amphetamine users have increased markedly in the past 4 years, the age group at risk is young (15-19 years), and sharing of equipment is common.

Responses by the WA ADA to needle use have included attempts to:

delineate extent of the problem by collecting data, testing on a voluntary basis, education of health care workers and clients, networking and liaison, production of educational and other materials, telephone information, counselling pre and post diagnosis, management, and referral.

Dr Saker stressed that no single agency had all the answers – there was a need for on-going and extensive networking.

Other key points raised were that many persons who shared injecting equipment, but who were not current drug users are infected with Hep C; many current and past IDUs with Hep C antibody have virus in their body and may develop chronic liver disease and that little is known about the non-metro area.

TOPIC 4 THE BLOOD BANK

Tony Keller, *Director of Red Cross in WA.*

The history of post transfusion HCV infection in Australia, particularly in WA was described. It was estimated that in Perth in 1988-9 the overall risk of post transfusion HCV infection was 1%. Specific anti-HCV tests were described, implications of their availability noted, and the high monetary and time costs required for current testing procedures.

The method by which risk factors in donors are assessed was described ie interviews on risk factors such as IVDU, time in prison, more than one lifetime sex partner, hepatitis or related symptoms, tattooing, etc. and a formal declaration is made regarding some factors.

Current major issues in transfusion associated HCV were noted: including: specificity and sensitivity of screening tests, availability of PCR, demands of counselling and monitoring, the question of lookback, and safety of blood supply.

TOPIC 5 A GENERAL PRACTITIONER

Dr Charlie Greenfield, *Senior Lecturer, Fremantle Hospital*

This entertaining delivery argued the necessity for focussing, and coordinating the delivery of preventive and treatment services by including community based GPs. The speaker queried that although the potential public health implications of HCV are well acknowledged, where was the willpower to get working on it? This was later illustrated by reference to the local fishing community as a) a high risk group due to high use of alcohol and IVDU, and b) in terms of transmission since they are young and heterosexual. "Everyone knows about it but nobody is doing anything about it!"

The need for further research on the nature of the disease, the distribution and relationship to other diseases, related behaviours (IVDU), high risk groups was mentioned. It was also noted that most current research is on current clinic clients but not a great deal is known about other risk groups.

Research involving GPs, pharmacists and other health professionals in the identification and treatment of HIV infection in the Fremantle area was briefly described. The model encourages patient choices and self determination, including the opportunity to contribute to knowledge in the field by participation in the research.

The speaker concluded, a multidisciplinary approach is needed, the size of the problem must be assessed soon, and a management plan is essential.

TOPIC 6 THE WA HEALTH DEPARTMENT

Dr Andrew Penman, *Assistant Commissioner, Health Department of WA.*

Aspects of the WA Health Department response to HCV were outlined. Some of the factors influencing policy formulation for HCV included: the unknown long term significance of disease in public health terms, the high expense of treatment, high relapse rates, synergism between HCV and alcohol use, and multiple risk factors.

In public health terms the next step was seen to be from drug trials to population based treatment for those infected or at risk. Objectives for such treatment included: virological cure, reduced infection, reduced end state liver disease. The latter two objectives were seen as the current priority for the Health Department. Emphasis was placed on the need for this step to be accompanied by a rigorous research orientation and some reservation was noted in relation to the widespread availability of interferon if adequate evaluation procedures were not in place. The speaker raised issues related to current interferon treatment eg cost barriers to individuals, and high anxiety for those who are uncured, the need to assist the uncured with managing aspects of their lives such as illness and infecting others.

Emphasis was given to the need for understanding the distribution of HCV in WA (particularly the distinction between prevalence and incidence). It was announced that the Health Department would commission research in this area.

TOPIC 7 A DRUG COMPANY PERSPECTIVE

Dr John Bertolini, *Schering-Plough Pty Ltd*

The main thrust of this delivery was to discuss the promotion of Schering-Plough's Intron A, the only drug currently approved for treatment of HCV. The promotion was described as having a strong education base (due to the poor state of knowledge about the disease) and would recommend targeting to those with the best prognosis.

The education program was designed to:

increase awareness of the disease eg main transmission routes; and place in perspective the expectation of cure. Promotion would be to three major groups : specialists (symposiums, clinical trials and studies eg at Westmead Hospital); GPs will not prescribe but diagnose and counsel and receive patients back for management (journals, monographs, diagnostic tables); the general community (pamphlets, posters to increase screening and dispel myths about HCV only being a disease of IVDUs).

The issue of price assistance for Intron A was discussed but its PBS listing is still to be debated.

SEMINAR UPDATE CONTINUED IN NEXT ISSUE

RECOMMENDATION FROM PROFESSOR FARRELL

People with HCV should seriously consider vaccination against Hepatitis B, as it is much more serious when one has a combination of the two diseases.

Report on Presentation to Professionals of Patient's Point of View

On April 27th, a meeting sponsored by Schering-Plough was held in Sydney and chaired by Professor Penny to which were invited a small group of representatives of government, private, university, and hospital medical professionals from Victoria, South Australia, ACT and NSW. We were allocated a five minute presentation and pointed out that there is a need for

1. **Education** More information for doctors, professionals and patients.
   Availability of literature on HCV in other languages and for other cultural environments (e.g for aboriginals and those in penal institutions.)
2. **More specialist availability** Earlier specialist treatment. Treatment for those in remote areas
3. **Acceptance of interferon** on the Pharmaceutical Benefits schedule
   Education of G.P.'s about its side effects.
4. **Availability of counsellors** who have been educated in HCV to help patients come to terms with what the disease may mean for their career, lifestyle and family plans.
   Availability of counselling for "significant others"
5. **Discrimination Issues** Education of the broader community to stop discrimination issues.
   A policy of safe nursing practice in all hospitals without isolation of the patient.

The presentation was well received.

A. Lamb

An alternative approach to worrying

A positive way to use up adrenalin is to win a few battles by tackling life and the problems it throws at you. The negative way is to stay awake all night, muscles rigid and adrenally saturated still because you've tackled no tasks, done nothing, lost every battle and are now lying there, worrying about everything.

Fear, anxiety, apprehension, panic, even over-concern, all whip adrenalin out into the bloodstream. Use it up by winning battles, understanding that this is the real way of nature. Find yourself ready to relax quickly and deeply, restoring energy, sleeping well, ready for the next battle.

Or would you rather take valium and suffer a reduced ability to fight back (even against major disease), so that even the thought of a battle has you tearing off another pill? Or trying any other form of avoidance that will even have a more permanent and long term destructive effect. These will only reduce your ability to even respond to those calls you need to in order to survive. Why not try taking a more positive approach and taking control of what you do even if you cannot control all the things around you?

Trudie

Harmful Herb

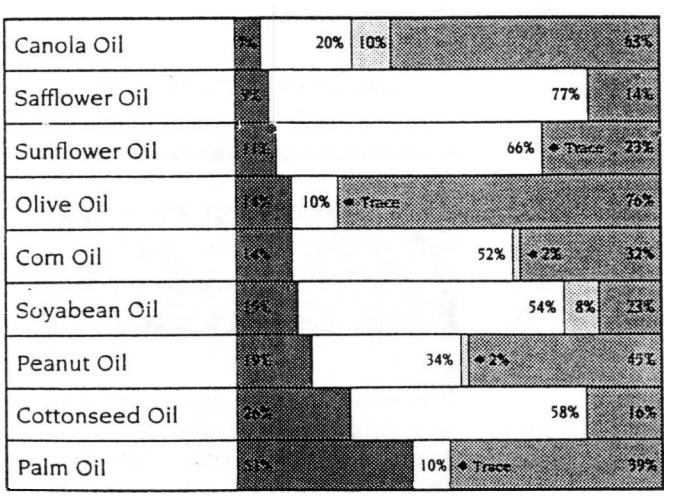
Tablets and capsules containing comfrey, a traditional herbal remedy for treating ulcers and inflammatory disease, have been withdrawn voluntarily from sale in Britain following studies linking consumption of comfrey extracts with liver damage. The move follows an investigation of the Department of Health's Committee on Toxicity of Chemicals in Food, Consumer Products and the Environment. The COT was particularly concerned about the levels of pyrrolizidine alkaloids in comfrey roots and leaves. These break down in the liver to form toxins.

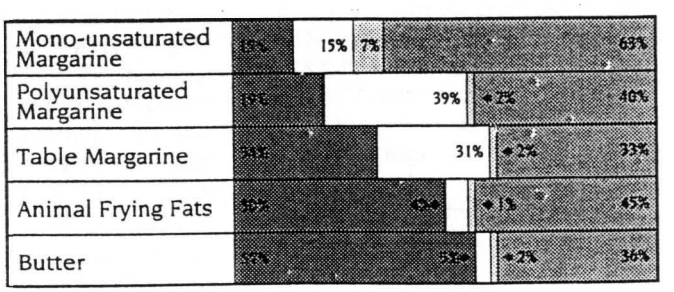
The committee discovered four reports of people becoming ill after eating comfrey. They developed a condition called veno-occlusive disease. "The veins in the liver block up and all sorts of damage follows," said a member of the COT secretariat. "Eventually people can die of liver failure."

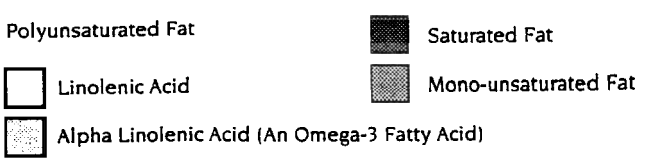
IMPORTANT

Enclosed with the Newsletter you will find a letter to the Minister for Health, Senator Graham Richardson for each member to post to him as part of our push for government funding.

COMPARISON OF DIETARY FATS







Source: Meadow Lea Foods