HEPATITIS C COUNCIL OF NSW

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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.

P.O. Box 98 Westmead, NSW 2145

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

Newsletter No. 5 **March 1993**

Professor Bob Batey addresses Wyong Support Group

Notes from an Address by Prof. Bob Batey, John Hunter Hospital and Newcastle University.

The following points are made to clarify issues covered in a previous summary of a talk given to a hepatitis C support group at Wyong.

1. Australia received its first kits for testing for antibody to the hepatitis C virus in patient's serum in August 1989. Since that time, developments have occurred making the test more sensitive and more specific. A patient who has recently contracted the infection, may still prove negative to testing for a period of several weeks with most patients becoming positive after ten weeks. It would appear from overseas experience that even with the latest testing, some patients may not develop antibodies for six months.
2. Recent studies from overseas have highlighted the fact that there are now several different strains of the hepatitis C virus. It is possible that these different strains may not give cross immunity but much more study needs to be done. The finding of these different strains may make the development of an effective vaccine even more difficult.
3. High risk groups for contracting hepatitis C include patients who have received blood products, IV users, and people exposed to more than one sexual partner in any 12 month period. There is a higher rate of hepatitis C infection in patients from Asian countries. The sharing of toothbrushes, razors or other equipment that may become contaminated by blood, could facilitate the spread of hepatitis C from a carrier to another person. Babies born to mothers who are hepatitis C antibody positive tend to have hepatitis C antibodies at birth but worldwide experience suggests the majority lose that positivity by 8 to 12 months.
4. In all groups of hepatitis C patients, approximately 20% have no obvious exposure to the virus.
5. Liver biopsy remains the only investigation able to identify the severity of liver injury in patients with hepatitis C. Liver biopsy is a procedure carrying a small but definite risk hence the need to keep patients under observation for a minimum of eight hours following the procedure. A liver biopsy allows the classification of changes into those of chronic active, chronic persistent and chronic lobular hepatitis, although with hepatitis C, less emphasis is made now on trying to define the difference between these patterns of inflammation.
6. 50% of patients contracting hepatitis C infection are asymptomatic. 50% of all patients contracting hepatitis C have the risk of becoming a chronic carrier of the virus. It appears to take 15 to 20 years of chronic ongoing hepatitis to develop the serious consequences of hepatitis C infection. These long term complications include the development of cirrhosis, portal hypertension or a high pressure in veins draining into the liver and a small risk of liver cell cancer.
7. Interferon remains the major drug available for the treatment of hepatitis C. Trials with another anti viral drug Ribaviran have been disappointing. The Newcastle Liver Clinic is one of many centres involved in the Australia-wide study of Interferon in hepatitis C and we all use a protocol compiled by the Westmead Liver Unit under the direction of Prof. Farrell.

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NEWS

We now have a Fax number as above - (02) 584 9194. We are also the possessors of a photocopier – a wonderful boon.

A new branch is to be formed on the Gold Coast of Queensland. We wish them every success.

It has come to notice that Adelaide is receiving quite a few grants from the National Health and Medical Research Council for research into HCV. We have practically no representation in that state, and HCV is not a notifiable disease either there or in WA.

However, in WA the Group is alive and flourishing as witnessed by the very successful workshop held on 17th February.

They had approximately 160 health professionals for the day and lectures from specialists in the field from other states. It is intended to hold another workshop later in the year. We hope to be able to publish extracts from the papers in the next newsletter, and there is to be a video made of the proceedings.

W.A. has also submitted propositions for funds from various government organisations in that state to help them subsidise their efforts. They have had help from the Drug and Alcohol Authority, the Aids Bureau, the Addiction Studies Unit at Curtin University and the Palmerston Centre. Submissions from the federal group to Canberra under the Community Organisations Support Services are proceeding, though slowly. NSW Health Department has promised the NSW Group the use of a Counsellor for HCV persons in the Western Area Health Service of Sydney.

Errata in last newsletter: In the article by Toni Irwin, please note the following – One can take Vitamin A as beta carotene in 10 times the recommended dose, but NOT Retinol – only up to 3 or 4 times the recommended level.

Vitamin B6 is water not fat soluble, but in large doses can damage nerve endings.

...from page 1.

The present trial uses Interferon in a dose of 3 million units, 3 times a week with a randomisation occurring after 3 months in those patients who have responded to the drug.

8. Cirrhosis is a permanent scarring of the liver that can result in a range of medical problems including fluid retention, jaundice, bleeding from the upper gastro-intestinal tract and impaired brain function leading to drowsiness and ultimately coma. Patients with cirrhosis can live for many years and may not need treatment for their condition.
9. **Transplantation and hepatitis C.** Many patients have been transplanted for hepatitis C. Many have done well but there is a high reinfection rate of the transplanted liver. Opinions vary now whether this infection is serious and rapidly progressive. Experience from Los Angeles suggests that many patients do not get into major trouble even with a reinfection of the transplanted liver.
10. The prescription of any drugs to patients with liver disease needs to be undertaken with a degree of care. Individual drugs are reported as causing problems in some patients but are often quite safe in others. Patients with liver disease should advise their doctors of their problem so that appropriate prescribing can be undertaken.

Naturopathic Remedies

In a letter received recently from a lady in Wellington, New Zealand, She states her father is convinced garlic cures hepatitis C.

"The virus has cleared itself from my father's body. He believes it has done so through the amount of garlic he has consumed over the years and the healthy foods. He rubs garlic on his toast, swallows it whole and adds garlic to his dinner meals.

We are writing to you to bring to your attention that perhaps garlic played a large role in cleansing the blood. Perhaps garlic is a possible cure, to be investigated more in the future."

Editor's note: It is good to hear that this man's virus has cleared. I wonder why there is still such a large percentage of Italian people who have HCV?

Should we include other hepatitis in our group?

There has been considerable discussion whether the Group should be expanded to include all hepatitis sufferers. A great deal of this pressure is coming from gastroenterologists who would like to include all hepatitis. We are very happy to have members who have other hepatitis viruses, and include this category on our membership forms now. They are welcome to any information we have, and we will help any such organisation as much as possible to get off the ground. I have suggested that the arguments for becoming a general hepatitis organisation should be put to members through this channel so that members can express their views.

However, the Sydney Group has voted to remain as Hepatitis C only for the following reasons:

1. The more restricted the area of interest, the more focussed the Group can be and therefore the more powerful in both educating others and in lobbying for their aims.
2. The issues of transmission and outcome with HCV are already blurred by inadequate knowledge and also so confused with HIV and HBV in the public's mind, that we need to be really sure about what we do know.
3. That our phone counsellors would find it an impossible burden to try to keep up with all information on all the hepatitis viruses and so we would not have enough staff to man the phone roster.
4. The implications of each "blood borne pathogen" are quite different, and if ignored, there is no reason why we should not all just come under the umbrella of HIV and AIDS.

It may be in the future that there will be an umbrella organisation that has branches of HIV, HBV, HVC and other blood borne diseases, but at the moment, no one has come forward to form such an organisation.

Supply of Herbal Medicines and Vitamins

A member in NSW is investigating if it is feasible to buy these wholesale and supply them at cut rates to members attending meetings. It looks as though there could be quite considerable savings to members because, as a charitable institution, we are eligible for exemption from Sales Tax.

If it is preferable for you to do your own shopping, you can use Russell's Healthwise Shopper, at the addresses opposite, by obtaining a special card that entitles you to 15% if you buy more than $50 worth on a Monday, or 10% at other times. You will not get a card or discount unless you identify yourself as a member of the Australian Hepatitis C Support Group.

Review of Literature

The *Australian Doctor* of (30.4.93) reported a study of four symptom free HCV carriers by Dr. Stefano Brillanti and colleagues from the University of Bologna in which they found that none of the four had any abnormal LFT's, histologic evidence of liver damage or signs and symptoms of hepatic disease during the three years they were followed. All were positive for HCV antibodies both at the outset and the end of the study. It was unlikely they all had intermittent viraemia detected each time they were tested. None of the four had abnormal liver enzymes in the 5 years before the study.

The finding that continuing HCV viraemia is not invariably associated with liver disease questions the belief that it invariably indicates liver damage, which previous studies had suggested. The study also raises the possibility that some HCV strains are relatively non-virulent. This has been raised before and the Italian study now bolsters the theory. Yet another possibility raised by the study is that the presence of HCV RNA in the serum does not necessarily mean that the liver is involved, but may reflect viral replication at a non-hepatic site.

We are grateful to Rita Lin for commenting on this study, she says: "Healthy HCV carriers in our experience are generally those who are HCV antibody positive, asymptomatic with normal LFT's and not viraemic. In Brillanti's study there are patients who are persistently viraemic with no evidence of liver disease. It would be of interest to know both the duration of the "disease" in this group of patients and also their mode of acquisition. In our experience, a large proportion of Italian patients are what we call "sporadic cases" (i.e. no known identifiable transmission route) and present with HCV at 40+ years of age with established chronic hepatitis on biopsy.

Follow up time in Brillanti's study was 3 years. HCV is said to be a slowly progressing condition although the rate of progession may differ among individuals. The natural history of HCV has been established for those who acquire it through blood transfusion but little is known about the natural history of HCV due to IV drug use.

Amongst our patients who acquired HCV through blood, the rate of deterioration is variable. Difference in strain virulence may help to explain some of these observations although to my knowledge there are no published data to confirm this. (Strain differences in responsiveness to Interferon, on the other hand, have been published in abstract form). While Brillanti's study is of course encouraging, the number of patients is small and the follow up time is short."

Oyster Alert

Oyster lovers in Florida are being told to give up their favourite food or risk death, particularly if they have liver disease. A bacterium hazardous to people with liver disease or a compromised immune system is ubiquitous in the warm waters around the Florida coast and gets into the oysters.

Vibrio vulnificus claimed 44 lives in Florida between 1981 and 1992, 35 of the deaths being associated with eating raw oysters. (New Scientist, 26.6.93)

The Health Department reports one death from eating oysters infected with this virus in 1990. It is relatively rare here, and now safety programs are in place to protect the public from infected oysters. This naturally occurring micro-organism is found in the coastal waters of eastern Australia, mostly between October to March where water temperatures are between 10-30 degrees, and salinity levels are 5-30%. People with liver disease are warned not to eat raw or partially cooked oysters. (Oysters Mornay or Kilpatrick are not always heated enough to kill all bacteria which may be present.)

Ozone Therapy

In July, the W.A. Group had a speaker on ozone therapy - Dr. Barnes, the only practitioner in W.A. The following points he made may be of interest to those who have asked about this treatment. It is taken from the W.A. Newsletter.

Treatment began in Germany, where it has been thoroughly researched for 40 years. However, it has not taken off, due to the facts that it is not very practical, cannot be packaged, and there are political pressures against it.

Ozone (O3) is a form of oxygen which is made by an electrical spark which converts the O2 molecule to O3. It cannot be breathed (due to toxins), and is powerful against bacteria, fungi and viruses (e.g. it is said that it is effective with HIV). It is speculated that the ozone affects the membrane of the virus as virus membranes are more sensitive than the membranes of normal cells). The ozone is administered intravenously as the blood acts as a carrier for O3.

A side effect is that OT creates more free radicals which are damaging to the tissues of the body so that patients must take beta carotene, and vitamins C and E, plus zinc, methomine (amino acid) and selenium.

The cost was said to be $40 per treatment for two weeks and it takes 40 minutes to administer.

The NSW Aids Council states "There has been no scienticic medical proof that this therapy is effective" Dr Buist says "Aerobic Ozone is Nonsense".

NOTICE

Annual membership fees are now due. If you have a red sticker on your envelope, it means that you need to pay us **NOW. This will be the only notice you will get before you are taken off the mailing list.** Those people who have joined since the beginning of June have no red sticker as they do not have to pay again.

A membership form is enclosed. If you do not have to use yours because you are a financial member already, please take it to your local health authority or general practitioner for them to photocopy and use for others with HCV.

Could anyone who has had a complete remission with Interferon treatment, please contact Chris Lawrence, Phone: (02) 820 1310, 50 Eagleview Road, Minto 2566.

It has been suggested that carrying a banner in the Mardi Gras Parade in Sydney next year would be good publicity for both HCV and the Group. There is a big pool of HCV in the gay community. Please let us know what you think by contacting either your local branch committee or Steve Hopper, at PO Box 98 Westmead 2145 or phone (02) 808 3646.

CONTINUED FROM PREVIOUS ISSUE

TOPIC 8 THE HEP C SUPPORT GROUP

Ms Ali Marsh, *Hep C Support Group*

Representing the views of those in the HCV support group, the speaker totally rejected the notion that lack of access to diagnosis was acceptable because there were not enough treatment resources. It was pointed out that if people are not told, they will also be anxious, and more importantly, the potential outcome of the disease can be affected strongly by delayed diagnosis (eg in relation to alcohol use).

The manner in which test results were communicated was also raised as an important issue in subsequent management eg telephone or mail informing of test results was deemed not to be satisfactory because the impact of knowing was often devastating. The need for better post test counselling was outlined.

TOPIC 9 PREVENTION

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

Prevention was recognised as a major part of the government's response to HCV in WA. The main focus for prevention was IVDUs, who constitute the largest high risk group. Evidence of positive behavioural changes by IVDUs in WA was noted, but also that unsafe behaviours continue. In particular, occasional unsafe injection was seen to contribute largely to transmission.

The notion that users modify behaviour according to perceptions of risk was presented and used to justify incorporating Hep C specific components in current disease prevention programs. Issues such as the effect of disease specific information on the impact of risk, and community tolerance and support for messages promoting safe use were raised.

An appropriate focus for prevention was seen to be specific behavioiurs and the settings in which they occur. Also it was seen to be more realistic to to concentrate on safe needle use rather then eliminating drug use. The question was raised: "Is it appropriate to expect that a reduction in needle sharing will have enough public health effect?"

TOPIC 10 PREVENTION RESEARCH NEEDS

Ms Wendy Loxley, *Research Fellow, National Centre for Research into the Prevention of Drug Abuse.*

This lecture covered notions of prevention classified as primary, secondary and tertiary and illustrated by the Public Health Model and the Health Belief Model. It was pointed out that research considerations, in relation to HCV include population characteristics, administration, compliance, data collection methods (interviews, questionaires etc.) analysis and presentation of results in terms of traditional quantitative, qualitative, environmental or evaluative research. The speaker concluded by listing the three main requirements for HCV research: finance, coordination and urgency.

TOPIC 11 IDUS COHORT STUDY

Dr Nick Crofts, *Head of Epidemiology and National Health, McFarlane-Burnett Centre for Epidemiology, Victoria.*

The speaker echoed the opening remarks of the seminar ie "Australia is doing well in relation to HIV" and added, "this can be repeated with HCV!".

The main focus of this delivery was the description of a study of IVDUs using drug users recruited from agencies (prisons etc) and social networks. Description of the method used to access "hidden" groups was followed by a presentation of selected results and discussion of related conclusions eg each year of injecting raises the chances of exposure to Hep C by 20%, and duration of use was found to be a more important predictor than age at which injecting commenced. Other factors associated with exposure and stages of HCV infection (eg a prison term, first injected drug was heroin, alcohol, and Hep B) were also discussed.

Comparisons between risk factors for HIV, HCV and HBV were made and it was concluded that different viruses move differently in different populations. This raised the question, "Who are the specific populations at risk of HCV?"

The speaker called for professionals in the HVC area to develop their knowledge of PCR because it is essential to current understanding of the disease.

Major prevention issues for IVDUs were seen to be : safe behaviour most of the time; identification of multiple sharing with multiple partners (eg prisons – needle sharing, tattooing) and; how to influence the process of new injecting.

In conclusion, an effective short term goal is to inject safely, not necessarily stop injecting.

SMALL GROUP DISCUSSIONS: FUTURE DIRECTIONS?

Participants were asked to consider "future directions" in terms of the questions: what is needed? who will do it ? and how can it be done?

Common themes to emerge from group activity included:

- prevention – much more needed.
- education – professional (including general practitioners) and public – awareness raising and training, peers, articles in Health Department and professional publications
- information – "everybody needs to know" – media messages
- research – epidemiological, virological, sociological
- management – access to services and treatment, including expansion of the role of GPs
- put HCV on the political agenda – "all public health issues are political" – eg by coordinated letter writing, direct approach to new Health Minister etc.
- coordination of response on all blood borne diseases and STDs
- utilisation of existing services eg those for HIV
- warning to potential suffers so they know of the risk now!
- expand response to include rural areas and "hidden" populations
- be ready for a public response to information – testing, appropriate notification methods, counselling etc
- regular forums eg in 1994 "What has changed?"

The concluding comments exhorted attendees to maintain the momentum of this seminar by doing something specific, (for example, inform one GP and one other person about HCV), and thus

"KEEP HCV ON YOUR AGENDA".

Synopsis prepared by Ms Anne Lockwood, Addiction Studies Unit, School of Psychology, Curtin University of Technology.

Stress

A year long study of 357 people by Stanford University Researchers, published in Health Psychology found reductions in stress, anxiety and depression levels of nearly 30% in those who exercised regularly. (S.M.H.1.8.93)