

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.

HEPATITIS C SUPPORT GROUP

NEWSLETTER

EDITION NUMBER ONE

21ST MAY, 1992

THE HEPATITIS C SUPPORT GROUP IS OFF AND RUNNING!

We have had an excellent response to publicity, and the number of telephone calls received indicate a genuine need for our group. In spite of a few hiccoughs with our answering system, there has been an almost overwhelming number of request for help, with over 70 enquiries. With this extra load on our resources, some spelling errors may have been made, or we may have missed someone when distributing information. We apologise if this has been the case and would appreciate your informing John Saunders (☎ 960 2318 between 7 & 10pm) so we can rectify the situation.

MEDIA COVERAGE

In the past two months, two television programmes have shown segments about hepatitis C. New South Wales viewers were shown a two part story on Channel Nine's Sydney Extra. This was followed by national coverage with a special on the ABC's 7.30 Report. The latter prompted enquiries from interstate as well as many local calls. Yes, we are now Australia wide! (or perhaps even international, if you consider we have had an inquiry from Malaysia).

Hepatitis C has been discussed on radio programmes in Brisbane, Canberra, Adelaide and Perth, and articles have appeared in the Western

Suburbs Courier, Wentworth Courier, Weekly Southern Courier, The Western Courier, The Manly Daily and La Fiamma. We will continue to make our presence known to other radio stations, newspapers etc.

NOTIFICATION

The Public Health Bulletin FACTS sheet containing information on hepatitis C, was to be released by the Department of Health earlier this year to all health outlets. However, it appears to be still languishing on someone's desk. We can only hope that it will be out soon.

It has also come to our attention that the present notification regulations only state "acute hepatitis". We feel this should be changed to "active hepatitis" as "C" is often not in an acute phase at the time it is detected, but is often active.

RESEARCH

We have requested statistics from the government about all notified hepatitis C patients. We hope to obtain gross figures of age, sex, post codes and nationality. This information should assist us to plan our strategies, and allow for more effective targeting of the target population.

AND MEDICAL RESEARCH

Dr. Rita Lin is using the polymerase chain reaction (PCR) technique in a research project currently undertaken at Westmead Hospital. She is testing the blood of patients who have had normal liver function tests (LFT) for over three months, to establish how infective they are. If you meet the criteria, and are interested in being part of the study, please contact her on 633 7705.

Rachael at Sydney University, is attempting to grow the virus in continual cell culture. If the project is successful, a plentiful supply of the virus would be available for scientists to work with to develop a vaccine. We wish her the best of luck.

Also at Sydney University, Janine Spencer is performing IgM assays in an attempt to distinguish acute from chronic infection. The project requires blood from people very recently infected. Anyone in this category who would like to assist should telephone her on 692 4037.

In the same department, Brad de Veries is working on needlestick injuries - so far with little success as there are fortunately so few. A recent report from Japan states, 3 out of 110 people with a needlestick injury became seropositive. This makes the incidence with the hepatitis C virus slightly higher than AIDS.

We are hoping that Dr. John Shea at Newcastle University will develop a study to look at the relationship between hepatitis C outcome and personality variables. Hopefully, this would give us valuable information on the benefits of relaxation and meditation. If the project goes ahead,

he would work in cooperation with Dr. Bob Batey from the John Hunter Hospital.

NEWCASTLE GROUP

We are very pleased to announce that a support group will be starting in Newcastle. People should contact Mrs. Leonie Shaw (who has been doing a great job) on 049 47 1206.

THE NATURAL APPROACH

Several members have been using natural remedies, ranging from seeking help from a naturopath to various herbal solutions, such as dandelion, milk thistle, nettle tea and ginger tea.

Meditation has also been used and it has been suggested at a Group meeting that it raises the natural levels of interferon.

PRECAUTIONS

A list of precautions that should be taken in the home can be found in the A.G.I. leaflet that is issued with the membership packs.

COMMUNICATION LINES

Help is need from the multilingual members of the group to deal with telephone enquiries from non-English speaking people. We have used the telephone interpreter services, but feel this is not ideal for personal conversations.

Would members from areas other than Sydney like to be put in touch with members in the same area? If you are interested, contact John Saunders on 960 2318 between 7 & 10 pm.

MICROBIOLOGY CONFERENCE

The Australian Society of Microbiology will be having their annual meeting in Sydney in July. As the topic of hepatitis C features prominently in the programme, we have approached the conference secretariat for permission to have an observer present. It has been suggested that a member of our Group speak about hepatitis C from the patient's point of view.

THE BLOOD BANK

We are continuing to liaise with the Blood Bank to improve the service for those recently diagnosed as having the virus and to acquaint ourselves with their procedures.

STOP PRESS

STOP PRESS STOP PRESS

JOBS REMAIN VACANT

I don't know what the newspapers are talking about when they say there are no vacant jobs. The Group has lots of jobs vacant; no pay but great satisfaction. To apply for any of the interesting positions listed below, simply telephone Sue Finn on 683 1726.

- Newsletter Editor
- Minute Secretary
- Telephone Support People
- Telephone Support Roster Manager
- Trainer for telephone supporters (required once every 3 months)
- Mail Officer (ie collects mail from post box to forward it)
- People to host coffee nights
- Someone to investigate incorporation.

At present, the following people are acting in committee positions;

Sue Finn	- Chairperson/ Treasurer
John Saunders	- Membership Secretary
Richard Booker	- Resource Maintenance
Audrey Lamb	- Community Liaison
Kath Perry	- Support Services
Susan Andrews	- Support Services

We are very grateful to Schering-Plough for their financial support to help us get going, and hope to obtain further sponsorship to relieve some of the financial burden of running the group.

CHANGE OF PHONE NUMBER AND ADDRESS

Our new address is:

The Hepatitis C Support Group
PO Box 98
Westmead NSW 2145
☎ 008 803 990 ☎

NEXT MEETING

3rd June, ☉ 6pm
☎ 18/8-10 Everton Road, Strathfield.
☎ 744 6945

The guest speaker will be Jeff Munday, Disability Programmes Officer, Dept of Social Security.

*** Please bring something to eat.***

Thanks to Anita Rosz for allowing us to use her house.

FUTURE MEETINGS

Future meetings will be held on the 1st Wednesday of each month, at different venues, to be advised.

1st July ☞ Dr Geoff McCaughan,
Royal Prince Alfred Hospital

5th August ☞ Speaker Rob Booker,
Counsellor, Sydney Hospital.

2nd September ☞ 1st Annual General
Meeting, when all jobs will be up for
grabs.

FROM THE EDITOR

By now you might be suffering from overload, so that's it for now folks! When we have filled the vacancy of Newsletter Editor, you can expect your friendly newsletter to appear regularly, keeping you informed about the latest news on topics of interest, eg interferon, nutrition, naturopathy.

☺ Audrey (584 2421)