

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 Support Group Inc.

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President's Report

It was with some trepidation I accepted the position of President of the Australian Hepatitis C Support Group last September. At that time we had only about 70 members, mostly in N.S.W., and a group had been formed in W.A. in the May. However, I am pleased to report the following developments and activities in the past 12 months.

We are now an incorporated body, registered as a charitable institution. This covers our office bearers throughout Australia for Public Liability Insurance, and exempts us from sales tax. It also means that any donations made to us are tax deductible and we can claim special rates for Telecom expenses. It was a lot of work to get this all through the red tape, for which we have Richard Booker mostly to thank. We have also negotiated a regular corporate sponsorship each month which keeps us afloat, along with your membership fees and other donations, and we have been able to buy a photocopier, fax and answering machine for the hotline, as well as pay some secretarial expenses.

During the year, membership in N.S.W. has grown to 239 with a pleasing increase in professional members; Victoria has its own branch with 53 members, and W.A. now has about 100 members. A branch is functioning on the Central Coast of N.S.W., and we have phone supports in country towns such as Lismore, Coff's Harbour, Kempsey, Taree, Port Macquarie, Newcastle, Wollongong, Lithgow, Dubbo, Orange, Glen Innes, Barraba, and Wagga. There are also a growing number of members in Queensland, with phone support in Cairns, Rockhampton, Sunshine Coast, and the Gold Coast. Tasmania has two phone supports, one in the north and one in the south. Canberra now has a phone support also, as has South Australia.

The people who look after the 008.803 990 information line are a wonderful group who do a sterling job, finding that they themselves feel better for having been able to help others. There are always vacancies for anyone who feels they can help, and they should contact Paul on (02) 360 7795. These people

have now been given professional training which has been invaluable and we have negotiated for further training in the future.

Our bonds with associated organisations such as the Australian Haemophilia Foundation and the various Drug and Alcohol Agencies have also developed well, and we have been well supported by the Australian Gastroenterology Institute. During the year, representatives of the Group have spoken on the patient's position to Drug and Alcohol authorities, medical groups, welfare agencies and health authorities, as well as to newspapers and television. If anyone would like to help with media please contact John on (02) 692 9560. At the Blood Bank in Sydney, a card with details of the Group has been developed and is to be given to those who test positive for HCV. Bernard (02) 449 7743 looks after this.

We are still trying to negotiate with both state and federal health departments, with little success, although we were granted an interview in N.S.W. Much more needs to be done in this area. However, the efforts of members, particularly country members, were tremendous in supporting the petition in N.S.W. and certainly raised the profile of HCV here. It is surprising that so little use has been made of our posters on notice boards in health services.

Our other major development has been the professional production of our newsletter every three months, thanks to Jon Browne in Melbourne, our graphic artist, who toils on to give us such an excellent presentation. Of course, contributions for the newsletter are always

Continued page 2

NOTICE OF ANNUAL GENERAL MEETING

The second annual meeting of the Australian Hepatitis C Support Group will be held on Saturday, 18th September at 2pm in the upstairs Conference Room, "Woodstock" Community Centre (an old mansion set back from the road in park like grounds) Church Street, Burwood.

Nominations have been received for the following positions:

President: Warren Wright
Vice President: John Mackenzie
Secretary: Stephen Hopper
Treasurer: Anita Rosz
Four Committee Members:
John Saunders,
Paul Harvey, Audrey Lamb

Other nominations must be received by Warren Wright, c/- P.O. Box 98 Westmead 2145 by 11th September.

This may be the last year the annual meeting of the Group will be held in Sydney - make it a memorable one!

All members and their friends and families are invited to attend, and several of us will be having a barbeque lunch from 12 onwards (gas facilities are available, as is play equipment for the kids.) If it is raining, we shall be eating sandwiches on the verandah. During the meeting we shall be showing a video and apart from the election of officers and presentation of short reports, discussing the future development of the Group. This is a time to get together in a more informal setting, and meet up with others perhaps in a similar situation to you. Could phone counsellors please make a special effort to be there, so we can get together again to check on how things are going.

This will also be the annual meeting of the N.S.W. Branch of the Group. Nominations are called for positions of Chairperson, Secretary, Treasurer, and two other members. Andre Van Altena has accepted nomination as Chairperson, Bernard Fischer as Treasurer, Chris Lawrence Committee member.

If country members are able to attend and have no accommodation, please contact Audrey (02) 584 2421

welcomed and comments on content or letters to the editor would be a change. If anyone would like to take on editorship, please ring Audrey on (02) 584 2421

Regular meetings have been held with a variety of speakers and topics, but small local groups in Sydney were tried once and did not seem to work due to the scarcity of coordinators in each area. This is a problem which needs to be readdressed in the future, as does more support for those who are starting on interferon, or suffering severe side effects of this drug. (We are endeavouring to get more acknowledgement of the need to study these side effects and what can be done to combat them.)

This year we have presented three submissions to the federal government for funding for a pilot study of needs of HCV persons to be done in Victoria, an information bank on latest research and treatments for HCV with access by computer, and a national secretariat. We also have an application for funding in N.S.W. under the Non Government Organisation Grants, which, if successful, will give us a full time coordinator/educator in 1994, with an office! Think positive and ask your local member to push for it. It would also be a model which may help other states.

We now have continuing contact with the New Zealand Support Group and are trying to contact the federal body in the U.S.A. and making enquiries if there are support groups in other countries.

This is a brief resume of some of the most important activities of the Group in this last year. For the success of these efforts there are many people to thank - each one of you doing whatever you can to advance knowledge and support for the cause. It is difficult to single out individuals, as so many have done faithfully whatever they could. Please accept my personal thanks for your support in what has been an extremely heavy year, and I am confident you will continue to support our new President and the other office bearers in the coming year. We have been congratulated on what we have achieved in such a short time in comparison with other groups which have started up, which is doubly amazing considering that all of us are suffering from ill health. We now have to increase our membership base, and establish small local groups.

Audrey Lamb.

Report from the Leura Conference

by Professor G. Farrell

The Leura Conference in early August brought together 50 gastroenterologists and hepatologists together with several virologists from around Australia. Visiting speakers were Professor Mario Rizzetto, the discoverer of the hepatitis D virus, who is also very active in hepatitis B and C treatment research, and Professor Robert Perrillo who has been involved with the major multicentre trials of interferon for hepatitis B and hepatitis C. At the meeting, the difficult issues concerning who should be treated with interferon, is interferon cost-effective, and which patients with hepatitis C are going to progress to severe liver disease, were discussed. New data from St. Vincent's Hospital Melbourne, suggests that the main determinant of whether an individual develops cirrhosis is how long he or she is infected with the virus. Patients who have been infected for more than 20 years appear to have about a 30-40% chance of developing cirrhosis.

The original finding of the Australian studies that patients with cirrhosis respond less well to interferon was reaffirmed at the meeting. It was generally agreed that patients with cirrhosis should definitely be treated. Indeed a cost-effective analysis by Mr. Alan Shiel of the Health Economics Unit of Westmead Hospital suggested that it might even be more cost-effective to treat patients with cirrhosis compared with those without cirrhosis. There was still some discussion as to whether patients with very mild liver test abnormalities should be subjected to liver biopsy, but there is mounting evidence that this was important even in the apparently mild cases to determine the severity of liver disease, since liver tests correlate so poorly with the pathological damage of liver injury.

The main area of difficulty with interferon treatment now is whether longer initial treatment will reduce the incidence of relapse. After six months treatment 60% of patients relapse but some studies are now showing that after one year of treatment (or after two years treatment in the case of one of the Australian Multicentre studies) relapse appears to be as low as 30% This issue will be the subject of on-going studies before general recommendations can be made.

Finally, there were several presentations about the basic structure of the hepatitis C virus, about advances in culture of the virus and about present knowledge concerning how this virus divides in liver cells. Although these studies are still very basic research into the virus is beginning to provide fundamental knowledge which will lead to the development of better antiviral drugs and perhaps in the future, other approaches to prevention, such as vaccination.

NEWSLETTER NOTES

We now have a Group in Canberra who have joined us and are willing to act as phone counsellors (during business hours) for HCV. It is ADD INC (Assisting Drug Dependents) and the phone number is (06) 247 3700. The persons to ask for are Judy Byrne or Diane Rumble.

☆☆☆☆

Westmead Hospital has appointed Jenny Campbell as Coordinator of Hepatitis Research. She is available on 633.6333, page number 819, and is the person to ask if you have any problems to do with HCV at Westmead. Some of her areas of responsibility include patient education, staff education and family studies to do with HCV.

☆☆☆☆

An article in NATURE, Vol 362, of 4.3.93 discusses the widespread use of Interferon in Japan where there are 1.5 million HCV carriers. (It is thought that the common practice of reusing needles in mass vaccination programmes several decades ago helped spread the virus.) It also mentions the dangers of using interferon in combination with traditional Chinese medicine, as there have been cases of pneumonia. Professor Farrell also warns of the dangers of the herbal medicine SHO-SAIKOTO SAINETO, which has been associated with interstitial pneumonia in HCV patients and is dangerous.

Summary of talk given by Dr. Robert Buist Ph. D.

We were pleased to welcome Dr Buist to talk to one of our meetings in Sydney on 10 February 1993, and he has given us permission to print notes from his talk. If you wish further information, you should consult Dr Buist privately at his rooms at Manly.

Dr Buist has his PhD in drug research and has had fifteen years clinical experience examining the ways in which nutrients and herbs can help chronic illness. At present most doctors measure "illness" of the liver by blood measure of liver enzymes (eg ALT, etc.) which are excreted when the liver is damaged, and how tender the liver is. However, there are other functional liver enzyme tests such as a salivary caffeine clearance test that gives good criteria of how the liver is detoxifying *before* damage to the liver. (Fluctuating ALT could mean that, due to the liver's great regenerative ability, it is recovering in between the damage occurring.) When there is damage to the liver, we generate free radicals. These cause damage to the body. Therefore, it can be useful to know the things we can do which are non toxic and which protect the liver from cirrhosis and cancer, thus keeping it functioning in a healthy way and avoiding production of free radicals.

Damage to the liver can be caused by viruses, chemicals (solvents, insecticides, herbicides, environmental pollutants), and other toxic substances such as alcohol and tobacco. (Regarding alcohol, a recent study⁽¹⁾ of long term mortality after HCV infection, shows that death may be more attributable to alcohol intake than to the virus itself.)

Vitamins that are anti oxidants protect the liver from free radical damage. These vitamins are Vitamin A (taken always as beta carotene, as this converts to Vitamin A only as much as the body can use hence avoiding vitamin A toxicity problems, Vitamin E (both A and E are stored in the liver) and Vitamin C. The recommended daily dosage is 30mg beta carotene, 500 international units of Vitamin E and 1/2-1 teaspoon (or 2 x 1000mg tablet) of Vitamin C one or two times daily. If you are inclined to acidity, do not take ascorbic acid, but take either sodium or calcium ascorbate. If you wish to increase your supply of calcium it may be advisable to take the calcium ascorbate. There is no

substance in the theory that large doses of Vitamin C cause kidney stones, it may however cause them to move. If you are prone to kidney stones, taking magnesium (elemental) to 400mg per day plus 100mg Vitamin B6 (always taken with other B vitamins) will prevent recurring kidney stones. If the liver metabolism is not good, there is more throughput of toxins into the kidneys. The other anti oxidant that is extremely useful is Kyolic Garlic - 5ml per day. Kyolic is a great stimulant for all aspects of the immune system. These anti oxidants not only protect the liver but other parts of the body as well from cancer.

Other liver nutrients are foods that are high in sulphur amino acids (such as found in fish, eggs and lentils) and methionine (one gram per day). These interact with our genetic material, and stop DNA damage caused by viruses. (2gms per day of methionine taken one week before and one day after surgery, can make a tremendous difference to those persons sensitive to anaesthetics.) Also advised are Folic Acid (folate) 500mcg per day and B12 Plus (eg Bioglan, 3 per day). Again, when taking any B vitamin, it is necessary to take other B vitamins as excessive intake of one suppresses intake of others. Calcium orotate and lithium orotate have been used successfully in Germany to prevent liver damage. The orotates have also been shown to recalcify bone metastases within 9 months. It is obtainable in 400mg tablets and one should take 1600 per day. Of the herbs useful for the treatment of the hepatitis viruses, the best known are *Phyllanthus Amarus*, which comes from South India and it slows anti viral activity. A report in the Lancet⁽²⁾ on its use with hepatitis sufferers tells of 59% who had lost their hepatitis B surface antigen in 15-20 days of treatment (compared with 4% of placebo subjects) with no significant side effects (note that this was hepatitis B).

Hypericum Perforatum (St John's Wort)⁽³⁾ has been used for the treatment of depression and has a potent activity against retro viruses. It decreases the ability of the viral particles to replicate. Both *Phyllanthus Amarus* and *Hypericum Perforatum* are anti viral herbs. Use one or the other.

Silibum Marianum (St Mary's Thistle) and *Bupleurum Falcatum* (a Chinese herb) are both used where there is a history or

presence of chemical/alcohol exposure, and so again one uses one or the other. *Bupleurum* lowers cholesterol and enhances the anti-inflammatory action of the body's own cortisone and has an inhibitory effect on the prostaglandins (which influence pain and inflammation). There has been shown to be significant improvement in liver functions over 6 months' treatment and improvement occurring during the first 2-3 months. When a person is on interferon and is having trouble with bacterial infections, *Hypericum* and Vitamin C (up to a level just before diarrhoea occurs) may be useful - the body absorbs as much Vitamin C as is needed for that particular virus at that particular time, depending upon stress levels). However, do *NOT* take any alcohol if you are taking interferon (including alcohol in herbal preparations).

Other useful information Dr Buist imparted was:

COLDS: As soon as you feel one coming on, take one teaspoon Vitamin C every four hours at first, then 3 heaped teaspoonsful per day until it is gone. As well, take Kyolic liquid (10-15ml) per day for the first couple of days. Also take minerals such as zinc and iron and Vitamins B5 and B6 (Bioglan Formula 4-3-tablets daily).

SHINGLES: Use intravenous Vitamin C for shingles - 30gm i.v. (slow 1 1/2 infusion) for four days, and then take 20gm orally for the next four days, lowering it to 10gm, then 5gm, then 2gm. This helps prevent the post shingles neuralgia, especially when combined with folic acid, 10mg and Vitamin B12, 10mg i.m. during the first 4 days.

ANTI-CANCER FOODS: All crucifers (cabbage, broccoli, Brussel sprouts, cauliflower) yellow and orange vegetables and fruit (for the beta carotene), beetroot, garlic and onion. For energy, eat raw fruits and vegetables as much as possible.

The measures of which Dr Buist spoke should be used also for protecting partners of HCV persons.

It was obvious that for a proper prescription for individual health, one should have an individual consultation with an experienced health professional who has knowledge of nutritional and herbal medicine.

References:

- (1) "Long Term Mortality after Transfusion-Associated Non-A, Non-B Hepatitis" *New England J. Medicine*, Dec. 31 1992
- (2) Thyagarajan S.P., et al: *Lancet* 2, 764 (1988)
- (3) Meruelo D., et al: *Proc Natl Acad. Sci (USA)* 85,5230 (1988)

TALKING WITH HEALTH PROFESSIONALS

Have you ever been to the doctor, or a health professional such as a nurse, social worker or dietitian, and come out feeling unsure whether that person understood what you meant?

Did you understand everything that was said to you? For example:

Did you understand everything the doctor said but when you arrived home you weren't sure whether you were supposed to take 2 tablets three times a day or three tablets twice a day or for how long?

This article is meant to help you make the most of your visit to the doctor or other health professional.

YOUR CHOICE

Generally when we are ill the first thing we do is see a doctor. Choosing a doctor who is right for you is important. Think about what you want from a doctor or medical service, for example, to be treated with respect as a whole person by the doctor and staff; a doctor who is approachable, who will discuss your problem and treatment with you, answer your questions in a language you understand and so on. Be clear about what you expect from your doctor and find the right one for you. Ask around, you have the right to choose.

YOUR PART

All too often we expect others to give us the answers to our problems with little or no effort on our own behalf.

You need to:

1. be able to say what you mean; and
2. make sure you get all the information you need.

Before your appointment:

Be clear in your mind the reason for your appointment. Before you go prepare a list of your symptoms, problems and concerns. Don't worry if these are vague feelings of ill-defined symptoms. They may be important for diagnosis. Include 3 major questions you need answers to.

When we are sick it helps to understand what the problems are, what treatments we need, whether tests are necessary and so on.

Many people don't ask for explanations because they think the doctor is too busy to be bothered with trivia, or won't have enough time to explain. This may be true. So use the time you do have with the doctor to your best advantage. Once things are clearly understood there is less worry and confusion. You can then use the time to get well quickly instead of worrying about misunderstandings or unknown tests etc. and this won't be wasting the doctor's time or yours.

The consultation

When your doctor says "Hello, what can I do for you today?" you can say "Actually there are a couple of things I'd like to talk about" ... and tell the doctor your symptoms (the things on your list).

We have given a visit to the doctor as an example, but these principles apply to all types of health professionals.

Tell the doctor about:

- any allergies or adverse reactions you've had to medicines
- medications you are currently taking
- treatments from other doctors, naturopaths etc.
- anything else you feel is relevant such as pregnancy, other medical conditions your doctor doesn't know about.

YOU HAVE TO ASK QUESTIONS TO GET ANSWERS

We are more likely to get what we want when we make an effort — especially to help ourselves.

The best way to get information is to ask questions!

Answers might come directly from the doctor or health professional, or they might come from various other sources:

- health department pamphlets
- leaflets from women's health centres
- health education courses in community
- health centres and women's health centres.

SOME SUGGESTED QUESTIONS TO ASK THE DOCTOR OR HEALTH PROFESSIONAL

You can use these to suit your situation. The ones marked with a star (★) could be your three major questions. Don't hesitate to ask anything else you need to know.

To find out the cause of the problem:

- ★ What do you think is wrong with me?
- ★ What do you think is the cause of this?
- ★ When will I begin to feel better?
- Could this be related to (stress, moving house, changing my job, my allergy or, smoking)?

Put in whatever you might be worried or just wondering about.

To find out about getting back to normal:

- How long do you think I will feel this way?
- Should I continue to go to work/sexual activity/hobby?
- Is there something else I can be doing to help me get back to normal quickly,

such as changing some of the things I eat or drink?

If the doctor says you need a test:

- What is the test for?
- How is it done and what will I have to do?
- How much will it cost?
- Is it necessary or is there another way of finding out.
- Will you let me have the results of this test?
- When should I phone you and ask for the results?

If the doctor gives you tablets or other medicine:

- Can you explain what these tablets / this medicine are for?
- Will they be all right with the other tablets I'm taking? (eg. contraceptive pill, others)
- What about drinking alcohol while I'm taking them?
- How long will I need to take them?
- Should I stop taking them when I feel better?
- Will the directions be clear on the packet/bottle?
- Will this affect my interest in sex?
- Will they make me sleepy or constipated or anything else?

Other questions:

- What sort of food should I eat?
- Anything else I should do or stop doing?
- Would relaxation or exercise help?
- When should I come back for my next visit?

Some other suggestions for your visit to the doctor or health professional:

- Choose a person you feel comfortable with.
- Remember they are providing a service.
- You are entitled to a clear explanation in a language you can understand.
- Don't say you understand if you don't.
- Don't be afraid to ask for a second opinion.

Produced by Health Promotion Unit, Westmead Hospital.

For those in NSW who have to supply their own needles and syringes, they can obtain these for free if they phone Sydney 331 2111 or, in country areas, 008 422 599. Say the size of the needle required (19 & 22) and 1 or 2 ml syringe. No need to state the reason for the needle - just that it is for personal use. Rubber gloves and condoms are available also. If there are no free ones available in their area, they will be advised which pharmacists will supply.