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

Newsletter No. 9 June, 1994

Patient-to-Patient Transmission Could Have Been Avoided

The possible patient to patient transmission of hepatitis C at a Sydney private hospital last year highlights the need for strict adherence to universal infection control procedures. The current NSW Health Departments "Guidelines for Infection Control" (revised in 1992) are sufficient to prevent the transmission of blood-borne viruses, such as hepatitis C and HIV, during surgical procedures.

The NSW Health Department's report on the investigation into this incident indicates the most likely cause of transmission was blood stained respiratory secretions. Studies have shown that up to 20% of patients undergoing general anaesthetic suffer minor trauma to the airways which results in visible blood on laryngeal masks. The NSW Infection control Policy for HIV/AIDS and associated conditions, published in 1992, states that "a filter for the anaesthetic circuit must be used to prevent cross infection ...". A Filter was not used in this case, providing a clear airway which could have facilitated this transmission. Salilvary transmission of hepatitis C has never been demonstrated.

The absence of any criticism of the hospital concerned by the Health Department is worrying. The hospital took seven months to notify the Health Department despite the facts that hepatitis C is a notifiable disease, and that in the acute form, which two of the patients sufferred, it is extremely rare. The argument put forward by Dr Catchlove that it was assumed these infections were aquired in the community and without "at risk" behaviour rather than through consecutive operations at the hospital must surely be questioned. Of 2,000 recently reported cases only 1 was acute. It is also usually much easier to identify the source of a recent acute infection. The Health Department did find the hospital's investigation to be inadequate and identified three more cases through its own investigations.

The failure of some doctors and hospitals to follow established "best practice" in relation to infection control has created an environment where this patient to patient transmission may be possible. Every patient has the right to know what infection control procedures are in place before undergoing surgical procedures.(For further comment see editorial)

Update on Hepatitis C

by Professor Robert Batey.

Information on the hepatitis C virus and its effects on those infected with it continues to grow exponentially. Hundreds of papers appear on the subject of hepatitis C from around the world and trying to keep up to date is becoming harder and harder. The three areas I will touch on here will be:

1.Newer tests for hepatitis C.

2. Current understanding of the significance of genotypes.
3. The position with respect to treatment in Australia.

NEWER TESTS FOR HEPATITIS C

The current tests are proving more reliable, sensitive and specific than the original test for hepatitis C and now one would hope that antibody tests would become positive within three months in the vast majority of patients infected with the virus. Most attention has recently been directed to testing for the virus itself and

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DON'T FORGET THE HEPATITIS C FORUM, AT DARLING HARBOUR, 22ND JUNE. FOR FURTHER INFO CONTACT CEIDA 02 818 5222

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at least two commercial products are now available which will give an estimate of the presence of viral RNA in serum. One test is based on PCR techniques whilst the other is looking at viral presence, utilising different technologies. The quantiplex assay by the Roche company does appear to allow workers to measure viral genome equivalents in serum in a reliable and reproducable way. Work has shown that if the serum contains less than 350,000 viral genome equivalents, the infectivity of that patient is much less and the likelihood of response to treatment is much greater.

Some laboratories in this country have already had experience using this technology and it would appear to be a dependable way of assessing the viral presence although other technologies are being developed which may supersede this approach. There is no doubt that we need to have access to assays for viral presence in patients who have normal liver function tests as recent work has suggested that many patients who have normal liver function tests do have virus circulating and do, on liver biopsy, have abnormal findings. This raises the issue of the healthy carrier state in hepatitis C.. Whilst inhepatitis B we can now quite accurately determine whether virus is present in serum, this is not so with hepatitis C and many patients with normal liver tests are actually carrying the virus in serum and serving as a source of infection. It is to be hoped that a measure of viral RNA in serum will soon become available for routine use in Australia.

THE SIGNIFICANCE OF GENO -TYPING AT THE PRESENT TIME.

Current evidence suggests at least a dozen subtypes of the hepatitis C virus in existence in the world. These subtypes are all distinct enough in their own right to cause infections in people who have been exposed to any of the other subtypes. The possibility of multiple infections with different strains of the virus has become an accepted fact with respect to hepatitis C infection. Hope has been expressed that different genotypes may be more sensitive to treatment with interferon but more recent evidence points to the fact that the viral load is perhaps more important in determining the severity of illness and responsiveness to interferon therapy. Much more work will need to be done before any final statements can be made about the significance of different genotypes in different subgroups in our community and in treatment outcome. A number of laboratories in Australia are currently attempting to define the genotypes responsible for infection in the different populations under investigation.

TREATMENT OF HEPATITIS C IN AUSTRALIA AT THE PRESENT TIME.

Currently everyone is aware that interferon is not available except to those who are able to afford the cost of the drug. A Task Force set up by the NH&MRC has been working hard to put forward proposals to the Federal Department of Health relating to the availability of this drug for patients with chronic hepatitis C. It would be hoped that that decision would be made regarding the availability of the drug sometime before the middle of the year.

Whilst much pressure has been exerted to have the interferon made more available, it has to be stressed that the long-term efficacy of this agent remains less than spectacular. There is no doubt that no other agent at the present time offers any real hope for patients with hepatitis C but a 20% to 25% long-term benefit does leave many people who try the drug disappointed when they experience a relapse.

Recent studies indicate that the longer the use of interferon, the greater the likelihood of a lasting response to the drug but, of course, cost factors come into play here. The excellent paper by the Westmead team has identified that cost effectiveness studies justify the use of interferon in patients with significant liver disease from hepatitis C. It is hoped that the drug will become more available in the immediate future. One word on treatment belongs to the

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EDITORIAL

It is believed that the possible patient-to patient transmission of hepatitis C at a Sydney private hospital occurred through anaesthetic equipment which was contaminated when an infected individual coughed during surgery introducing blood stained respiratory secretions into the re-usable part of the anaesthetic circuitry. This then acted as a reservoir for the virus which could have been transmitted to the other 4 patients as droplets via minor breaks in the lining of the mouth and throat when the equipment was used for them.

The anaesthetist admitted that neither viral nor bacterial filters had been used during the procedures. This was in spite of the NSW Infection Control Policy published in 1992 which states that "A filter...must be used to prevent cross infection of the anaesthetic circuit."

It is frightening that patients should enter a hospital for medical treatment and be discharged with a potentially fatal illness such as hepatitis C. It may be speculated that this is not an isolated case and the question needs to be asked, is it happening elsewhere, and if so, how often. While infection control guidelines in NSW are cited by the Health Department as being among the most stringent in the world, it does not seem unreasonable to suggest that something is going terribly wrong with their implementation. The assessing compliance with the infection control policy and associated legal and enforcement issues. It can only be hoped that this review occurs quickly so as to prevent further patient to patient transmission of hepatitis C.

The Health Departments policies and guidelines regarding infection control do not have the force of law in private hospitals in NSW. Earlier this year the government passed the Health Legislation (Miscellaneous Amendments) Act 1994 which enables regulations to be made concerning the standards for controlling infection which must be followed by dentists and doctors. This power is designed to enhance protection of patients against HIV, HCV and other infectious diseases and may involve the mandatory adoption of published health standards and infection control guidlines. It is reported that the legislation will enable fines of up to $25,000, deregistrations or restriction of practice of healthcare workers who fail to follow these guidelines.(Capital Q Weekly, 13 May, 1994.)

In view of the apparent failure to comply with the policy in the patient to patient transmission of hepatitis C, it would appear that the Minister would be justified in using these powers at the earliest opportunity. There is no reason why the practices of doctors should not be regulated in this way, together with strict monitoring of compliance.

Doctors who do not comply with infection control procedures endanger their patients lives. Their right to treat patients should be forfeited and they should be prosecuted.

When the first patient to patient transmission of HIV was confirmed last year the AMA called for the introduction of compulsory testing of all surgical patients for HIV. This is a scurrilous ploy to place the blame for such transmissions on patients. It is a patients right not to disclose their infectious disease status. It is the doctors duty to comply with infection control procedures whether or not they are aware of the patients status. Testing will not discover infections in the window period. All patients should be presumed to be infectious. Our group supports the right of patients not to disclose their HCV status and to know that infection control procedures are in place and complied with. (Written by Warren Wright, President).

St Mary's Thistle

In a recent bulletin of the Adverse Drug Reaction Advisory Committee it was reported that a man taking St Mary's Thistle and other medication had sufferred liver damage. The Australian Herbalist Association believes that this report has no scientific basis from which to draw an adverse concicusion and in conjunction with the Australian Natural Therapists Association continues to recommend St Mary's Thistle.

Social Security

- Ignorance lifting.

Ignorance of the symptomatology of hepatitis C has been an enormous barrier faced by symptomatic people who cannot work full-time and who seek income support from the Department of Social Security. Primarily through our involvement with the Hepatitis C Support Group, the Welfare Rights Centre has recently been able to assist several people with HCV in their battles to secure Diability Support Pension.

Anyone whose symptoms prevent full time work (defined as work of at least 30 hours per week) should qualify for Disability Support Pension (DSP), subject to income and assets tests. A major problem for people with hepatitis C in accessing DSP has been ignorance of the symptomatology of hepatitis C on the part of the Australian Government Health Service. This ignorance has meant that the extremely debilitating symptoms that can be associated with hepatitis C, such as chronic nausea and fatigue, tend to be discounted by Commonwealth Medical Officers (CMOs) when assessing the claimants "impairment" under the Impairment Tables of the Social Security Act. The result has been that some people whose symptoms preclude full-time work either exacerbate their symptoms by remaining in work, or are forced to look for full time work in order to qualify for Job Search Allowance.

Welfare Rights Centre wrote to the Secretary of the Department of Social Security seeking amendment to the tables, so as to enhance access to DSP forpeople with hepatitis C. We were pleased to receive a prompt reply to our letter, which addresses our concerns and lends support for the amendment proposed.

It is essential that anyone with HCV, who feels incapable of working a 30 hour week and who is applying for social security income support, is informed as to the problems in establishing eligibility. Reprinted on page five are the two impairment tables relevant to HCV. If you are claiming DSP, give your treating doctor a copy of these tables and ask him or her to include an assessment of your impairment rating in the medical submission with your claim. This will ensure that Table 25 (see page five) is <u>not</u> ignored, as has been the tendency to date.

If you need further advice, or assistance appealing a social security decision, contact the Welfare Rights Centre on 211 5300 or 008 226 028. We can also send you our Fact Sheets on Disability Support Pension and Sickness Allowance.

Update on Hepatitis C

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study being considered at John Hunter Hospital in Newcastle. A proposal will be put to the Ethics Committee in May to allow a study of the use of traditional chinese herbal medicine in a small group of patients who, at this stage, are not able to gain access to interferon. Studies from China indicate that therapies can lead to normalisation of liver function tests in hepatitis B and in addition, a significant number of patients convert from hepatitis B e antigen positive to e antibody positive. The principle of the therapy relates to hepatitis of any sort and thus a trial will be proposed comparing the traditional medicine with an identical placebo product in hepatitis C. Anyone interested in further information regarding the protocol should telephone me at the John Hunter Hospital in Newcastle.

The address for contacting Dr Batey is: Dr R Batey, Director, Gastroenterology Unit, John Hunter Hospital, Locked Bag 1, Hunter Region Mail Centre, Newcastle NSW 2310

Thanks to Professor Batey for the article and for taking our concerns to the Task Force.

Special Thanks to Linda Forbes and the Welfare Rights Centre both for the article and the advice and assistance offered to people with hepatitis C.

Schedule 1B. Tables of Impairment. Social Security Act.

TABLE 16. LIVER AND BILIARY TRACT IMPAIRMENT

Impairment rating	Criteria
NIL	Mildly abnormal liver function tests but good nutrition and strength and no other signs of disease.
FIVE	Signs or stigmata of liver disease BUT no history of jaundice, ascites or bleeding oesophageal varices within the last five years. Liver function tests normal or mildly abnormal.
TEN	Signs or stigmata of liver disease with jaundice, ascites or bleeding oesophageal varices 1 to 5 years ago BUT normal to mildly abnormal liver function tests.
TWENTY	Signs or stigmata of liver disease with jaundice ascites or bleeding oesophageal varices 1 to 5 years ago AND markedly abnormal liver function tests.
FORTY	Signs or stigmata of liver disease with jaundice, ascites or bleeding oesophageal varices in the past year OR objective signs of progressive liver disease.
FIFTY	Permanent irreparable biliary tract obstruction.
SIXTY	Objective signs of progressive liver disease with ONE of the following: * persistent jaundice * frequdent, recurrent bleeding episodes * central nervous system manifestations of hepatic insufficiency.
SEVENTY	Objective signs of progressive liver disease with TWO of the following: See sixty
EIGHTY	Objective signs of progressive liver disease with ALL of the following: See sixty
NINETY-FIVE	Hepatic Coma

TABLE 25. MISCELLANEOUS IMPAIRMENTS, FOR EXAMPLE MALIGNANCY, HYPERTENSION, HIV

NOTE: Persons with Group III and IV HIV infection are usually manifestly incapacitated for work.

Impairment rating	Criteria
NIL	Controlled hypertension. Minor symptoms which are easily tolerated.
TEN	Mild to moderate symptoms which are irritating or unpleasant but which rarely prevent completion of any activity. Symptoms may cause loss of efficiency in some activities.
FIFTEEN	More severe symptoms which are more distressing but prevent few everyday activities. Loss of efficiency is discernible elsewhere. Self-care is unaffected and independence is retained.
TWENTY	Marked lose of energy leads to avoidance of many daily tasks, most of which can be completed but rapidly cause fatigue. (eg malignancy)
THIRTY	Loss of efficiency discernible in many everyday activities. Some elements of self care are restricted but in most respects independence is retained. Malignant hypertension - severe, uncontrolled. Inoperable, asymptomatic but potentially life threatening aneurysm or malignancy.
FIFTY	Major restrictions in many everyday activities. Capacity for self care is increasingly restricted, leading to partial independence on others.
SIXTY-FIVE	Most everyday activities are prevented. Dependent on others for many kinds of self-care.Able to 1 be maintained at home with considerable assistance and frequent medical care.

YOUR LIVER

Your liver is the largest organ in your body and plays a vital role in regulating life processes. It is a complex organ which performs many functions essential to life.

Location of the liver.

The liver is located behind the lower ribs on the right side of your abdomen. It weighs about 3 pounds and is roughly the size of a football.

Functions of the liver.

1. To convert food into chemicals necessary for life and growth.

2. To manufacture and export important substances used by the rest of the body.

3. To process drugs absorbed from the digestive tract into forms that are easier for the body to use.

4. To detoxify and excrete substances that otherwise would be poisonous.

Your liver plays a key role in converting food into essential chemicals of life. It is a vital organ for the production of energy in the body. All of the blood that leaves the stomach and intestines must pass through the liver before reaching the rest of the body. The liver is thus strategically placed to process nutrients and drugs absorbed from the digestive forms which are easier for the body to use. In essence, the liver can be thought of as the body's refinery.Your liver also plays a vital role in removing from the blood ingested and internally produced toxic substances. Further, drugs taken to treat disease are also chemically modified by the liver.

Your liver helps you by:

- Producing quick energy when it is needed
- Manufacturing new body proteins
- Preventing shortages in body fuel by storing certain vitamins, minerals and sugars
- regulating transport of fat stores
- regulating blood clotting
- aiding the digestive process by producing bile
- controlling the production and excretion of cholesterol
- neutralising and destroying poisonous substances
- metabolising alcohol
- monitoring and maintaining the proper level of many chemicals and drugs in the blood
- cleansing the blood and discharging waste products into the bile
- maintaining hormone balance
- helping the body resist infection by producing immune factors and by removing bacteria from the blood stream
- regenerating its own damaged tissues
- and storing iron.

LETTER TO THE EDITOR

After reading the "current" newsletter (March, 1994), I felt upset and angry that many people cannot get on the Interferon and Wellferon treatments. Yet, I was in the process of getting on it myself, until I learned of the side effects - the effects of treatment are debilitating - I believe it was in my best interest to refuse it. Because: I live alone, I don't have a partner to look after me or friends to live with me. The idea of having treatment felt (and still feels) isolating. What could I do ?

I told of my situation to the Gastro. Nurse, Jennifer Campbell, who talks to people on the treatment, and she agreed with me that it wouldn't be a good idea for me to go on it.

Where does that leave me ? Am I lucky to miss out on the side effects and isolation? Or do I miss out on doing something about my HCV?

I guess I'm trying to say there's another side to people "missing out" on treatment, and there's no support, and the side effects are not fully disclosed or talked about.

Kay Donaldson

Do you live in the Outer Western suburbs? Would you like to attend group meetings in the St Mary's / Penrith area? If the answer is yes, please contact Herby Westpfahl on 047 32 3214 . Herby lives at Kingswood and is very keen to set up a support network in his area.

PLANNING SUB-COMMITTEE

by Paul Harvey

On 29th April, a Planning Sub-committee (PSC) was formed to develop a Strategic plan for the organisation, consider funding applications and work towards raising the organisational skills of the Management Committee. This all ties in with the transformation of our group from a volunteer based group to a fully professional organisation and will enable us to operate within government funding guidelines.

From my involvement in the PSC I have gained a clearer understanding of what committee work entails. Previously, because I was unsure of the processes and demands of committee work, I had been holding back from making a strong commitment.

Through my work with the PSC, I now realise that committee roles and duties are quite finite, rather than bottomless pits of bother. I've also found that commitment has its rewards which for me include: Status, practical experience (which adds to my TAFE studies), feelings of accomplishment and pride, and hey, I've made some good friends along the way.

To break down the distance between membership and mangement, in each newsletter I'll report on what we've been covering in our development program.

We started by looking at the role of the group and the needs to which the group responds. We then analysed the responsibilities of the committee, both as a whole, and as individual office bearers. We obviously, offer many different services and these each represent opportunities for member involvement. There are, for example, the areas of peer support, lobbying, advocacy, counselling and information resources.

You may not wish to commit yourself to the management committee, but if your a closet journo, you may like to do some work with the committee member responsible for media and public relations. Likewise, if you enjoy working with people on a personal level, you may like to do a little counselling or assist with some administration work for counsellors.

This organisation will soon be expanding . We will need outside professional help and more membership involvement. A specific task for our PSC is to assist in your involvement, identifying areas in which you can help and preparing guidelines for that work.

Success in our organisation relates to three things:

- Commitment
- Skills
- Planning.

Most of us have the first two. It is the management committee's responsibility to provide the planning and co-ordination and support.

Individuals are the crucial resource of our organisation. The group needs YOU, and what it offers you in return is the chance to learn and belong. Please let us know what you want from our organisation.

H E L P !

WE NEED YOUR SKILLS

If you have good organisational skills, computer/typewriter, filing, telephone or personal communication skills and you can spare a few hours per week, our organisation needs you ! Our office in Surry Hills (just up the street from Central Railway Station) is swamped with work and any help would be greatly appreciated. We have applied for further administrative support in our latest funding application, but even if its accepted, it won't happen until next year. Meanwhile the organisation is growing and we have only a part-time co-ordinator to meet our needs. If you could come into the office for a few hours just once a week, the help would be invaluable.

If you can help please contact Jennifer on 02 212 1854 during business hours.

BIG THANK YOU TO KAY DONALDSON

Kay comes into our office once a week for half a day and puts into practice the skills she is learning at TAFE and of course is of invaluable assistance to Jennifer Horton, our Group Co-ordinator.

IMPORTANT ANNOUNCEMENTS

SPECIAL GENERAL MEETING 18TH JULY, 1994 AT 7PM

AT

THE QUAKERS HALL (UPSTAIRS), 119 DEVONSHIRE ST, SURRY HILLS

GUEST SPEAKER: ROB BOOKER, LIFESTYLE COUNSELLOR

At this meeting the following resolutions will be considered and voted upon :

1. That the name of the association be changed to the HEPATITIS C COUNCIL OF NSW.
2. That the objects of the association be changed so that activities of the association are limited to NSW rather than Australia wide.
3. That the procedure for amending the rules or passing special resolutions be changed so that such resolutions may be passed in the following manner:

> *A special meeting will not be convened. Instead, a notice and voting paper will be sent to all membersfor return to the association within 28 days of the date of the notice and the resolution will be determined by a count of the votes which are returned.*

4. Adopt new aims and objectives.

COFFEE NIGHTS - 29th June, 1994 - 7.30pm

A number of members in Sydney have expressed the wish for an opportunity to just get together and talk to other members of the group. In response to this wish three members have offered to open their homes and invite people in for Coffee! Talk about fairy godmothers (and fathers)! If you would like to attend one of these coffee nights please contact one of the following people - Anita Rosz on 02 744 6945,. Bernard Fischer on 02 449 7743 or Henry Brun on 02 389 7648.

Did you know that oestrogen based contraceptive pills are contraindicated if you have *severe* liver disease or if your ALT levels have been raised in the previous three months. If not DO NOT PANIC. But perhaps you should discuss this with your doctor on your next visit.

BIG, BIG, BIG, BIG, BIG, THANK YOU

TO ALL THOSE WONDERFUL PEOPLE, METRO, COUNTRY AND INTERSTATE WHO GIVE SO FREELY OF THEIR TIME AND THEMSELVES TO ACT AS VOLUNTEER PHONE COUSELLORS TO PEOPLE WITH HEPATITIS C.

PLEASE TAKE NOTE

As from the 19th July, 1994 the 008 Support Line will operate for NSW only. The organisation can no longer afford the enormous costs of an Australia wide service.