

# 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 TWO

21ST SEPTEMBER 1992

### A BRIEF HISTORY OF THE HEPATITIS C SUPPORT GROUP FORMATION

In November last year, a group met at Westmead to discuss the formation of a support group. Present were Sue Finn, John Saunders, Kath Perry (representing the P.R. Company who advises Schering Plough), Genevieve Latchford, Kerry Goodworth and Audrey Lamb. We decided the first thing to do was to try and get the public more aware of the disease and how it should be handled.

There have been T.V. interviews, for example on Sydney Extra and the 7.30 Report, and numerous radio and press releases throughout New South Wales, particularly after it was found that 10 persons had contracted Hepatitis C from blood transfusions in Gosford since screening of blood was introduced.

As a result, the 008 Information Line was set up on 18th May, 1992, and during the next 2 month period handled an average of 8 calls per day. It was staffed by Yvette and Helen from the P.R. Company for whom Kath Perry worked, and was largely paid for by Schering Plough. Now it is answered by a recorded message asking the callers to ring the person on phone roster for that morning, afternoon or evening. At the moment, we are still using the answering machine generously lent to us by John Saunders. Thanks too to Paula Cutting, Kay Donaldson, Bernard Eddy, Bernard Fischer, Kerry Goodworth, Larissa Kaganov, Susan & Mark Knowles, Audrey Lamb, John Saunders, John Taylor and Andre Van Altena for their phone duty.

Meanwhile, we have held meetings for our members and interested members of the public. Professor McCaugghan and Dr. Chris Liddle have spoken; videos of disease processes of Hep C have been shown; Rob Booker, a grief counsellor from Sydney Hospital has discussed the conflicts we all face; and a spokesperson from the Department of Social Security has addressed us. Anita Fosz has very kindly lent her home for several of the meetings, and others have been held in a cafe and at Westmead Hospital. We are not sure where the best place to hold meetings is, nor the time of meetings.

We have had posters distributed and put up in Drug and Alcohol Centres, thanks to the efforts of Steven and Sharlene Ivins who have photocopied a lot of material for us.

We have sent out hundreds of information packs and have had to make the decision to only send out the Public Health Sheet, a Hepatitis Glossary, and our membership form in response to phone requests, and to impose an extra charge of \$5 for the big pack, as it was costing \$4.35 in photocopying and postage to send out the latter, and many people were receiving them and not becoming members or sending a donation.

There is now a support group set up in Perth, as well as one in Newcastle and on the Central Coast of New South Wales. We have contacts in each of the states (and also in each area of this state) who have agreed to be the contact person for their area, and we are hoping that they will eventually form groups as the numbers become appropriate.

At the Inaugural Annual General Meeting held on 8th September, the following Committee was elected: Audrey Lamb (President & Publicity Officer), John Saunders (Membership Secretary), Sharlene Ivins (Treasurer and Head of Fund Raising Committee), Richard Booker (Vice President), Pam Smith (Mail Officer), Bernard Eddy, Jeff Merritt and Anita Rosz.

At that meeting it was decided to go ahead with incorporation of the group, so that we gain more financial credibility. Other matters decided were:

1. In order to try and meet more of our expenses, fees should be raised to \$25 & \$10 and be due on 1st September each year.
2. We should pursue fund raising ideas.
3. A position statement should be prepared on the Group's attitudes to Interferon and the role the Health Department should be playing with Hepatitis C issues (to be used by everybody in talking to politicians, media etc.,) and
4. More local meetings be held by a coordinator in each area, and general meetings with speakers be held, say, once every three months.

It was gratefully acknowledged what a tremendous support Schering-Plough, the staff at Edelman's and Professor Farrell and his secretary, Diane, have been to the Group.

#### NEW VACCINE - REPORT FROM THE ITALIAN NEWSPAPER (LA FIAMMA) 16/7/92

There is going to be an experiment in Italy next year of a new vaccine for Hepatitis C. One English microbiologist, Michael Houghton, recently tried the medicine on a chimpanzee in the U.S.A. and he announced at the world conference for Hepatitis C held in Venice in June of this year, that the results from the chimpanzee study are encouraging for future control of the HCV virus.

At the moment, it is too soon for the experiment to be tried on people, and when it does, it will probably be tried on those volunteers who are already infected with the HCV, and it is anticipated that the vaccine will weaken the Hepatitis C. Dr. Haughton said that it is very logical to experiment with chimpanzees first as they are similar to humans in many ways. The vaccine does not yet have a name and will be a bit expensive. However, Interferon is also very expensive, costing between 6 and 12 million lira per person (\$6-12,000 Aust. In Australia, the cost is \$3-4,000).

There is an alarming risk of Hepatitis C in Italy. Two million have the virus (of a population of about 65 million). In North Italy, one in 100 persons suffers with Hepatitis C, and around the area of Venice, the incidence is 3-4 in 100. However, only 4 in 1,000 die each year of cirrhosis, and 70-80 in 1000 die with chronic active hepatitis. (In Australia, in a recent paper, Professor Farrell estimates that there are 50 thousand with Hepatitis C infection, and 25% of these will die of decompensated cirrhosis.)

## REVIEW OF THE USEFULNESS OF INTERFERON TREATMENT

A recent paper by Professor Farrell in the Medical Journal of Australia, Vol. 156, June 15 1992, was a review of the usefulness of Interferon treatment for chronic viral hepatitis. Professor Farrell, basing his statistics on the prevalence of Hepatitis C in healthy blood donors, estimates that there are 50,000 persons in Australia with HCV. He predicts that patients will present at a median age of 40 years and will include about 1500 new patients a year for the next 20 years.

The number of newly infected persons should be less as a result of blood screening for transfusions, and it will also take between 10 and 45 years for these infections to result in endstage liver disease or PHC. Cost of a liver transplant is about \$75,000 and palliative management of endstage liver disease is even more costly than liver transplantation.

50-60% of patients who acquire HCV by transfusion of blood products become chronic carriers, and about 40-50% of chronic HCV carriers have chronic active hepatitis. The remainder have less severe forms of liver injury, but of the total 20% of patients go on to develop cirrhosis. Usually, cirrhosis takes a median time of 18 years to develop and PHC 24 years. Sporadic cases of HCV account for only 12% of chronic Hepatitis C in Australia, but it is the major association in countries where HCV is even more common, such as Italy, Spain, Egypt and Japan.

Some groups of patients have a more favourable response to Interferon treatment than others. Patients with mild chronic active Hepatitis C (usually acquired by injectable drug use and presenting at a younger age) had an 80% response rate to Interferon and 40% of these patients had a long term response. This finding has been confirmed by a recent French study. Chronic persistent hepatitis has also been shown to respond favourably to Interferon. The optimal treatment for Hepatitis C will be antivirals which can be taken orally (Ribavirin has shown some promise, but does not seem to produce long term responses.)

## SUMMARY OF ROB BOOKER'S TALK

At the last meeting we had an excellent talk by Rob Booker, Counsellor at Sydney Hospital and also in private practice. Here are some notes taken by John Saunders which could be of interest to those who were not able to be there.

Rob spoke of the effects on us of having a disease like Hepatitis C, and the need for emotional support that this engenders.

He talked of the uncertainty and anxiety each of us face to a greater or lesser extent when we really know so little about the disease. This scarcity of information increases our problems.  
Remedy: healthy lifestyle and stress management.

We need some technique for dealing with crisis management - anniversaries often cause increased anxiety as we wonder what next year will bring. Fatigue and absence of our own powerfulness often leads to depression, as does the normal grief reaction when we are given our diagnosis. In this situation, grief (even if not acknowledged) is to be expected as we face a continuing loss of quality of life and independence, and for some, a curtailing of ambitions and relationships, as well perhaps, as a fear of dying. The medical interventions necessary can lead us to feel a loss of personal self worth, and this is particularly so when others treat us thoughtlessly as "lepers".

Remedy: Sharing and counselling. Do not bottle feelings.

In fact, one of the most difficult things to deal with is the change in some of our relationships. Where we had thought we would have support, we are left with a feeling of betrayal. Or we can feel a sense of guilt that we will not be able to do the things for our partner or children that we feel we should. Maybe there is also a sense of guilt that we may possibly infect others.

Remedy: Learn to take responsibility only for self, not others.

Positive things to do:

Avoid stress any way you can as the immune system is damaged by stress. This does not mean bottle things up and give up but -

- \* Know your rights in the hospital system.
- \* Learn to be politely assertive.
- \* Learn to wait patiently for test results.
- \* Think carefully about disclosure of your condition to other people - do they really need to know?
- \* Do anything that helps build your self esteem - give up any notions of unworthiness, tap into your own inner integrity.
- \* Reward yourself and be self indulgent - you are the best person to look after you. Spend some of your income and your energy on yourself.
- \* Have social involvement with others.
- \* Take exercise as this lessens depression even if you think you are too weary to do anything.

Rob also suggested that maybe we should start our group meetings with an ice breaking game, and close with a short ritual.

Rob saw the Group as maybe providing as well as the above:

1. Access and constant support for significant others - their needs are not often looked at.
2. Access to ongoing counselling in more depth.
3. Provision of information to the general public.
4. Provision for support for the carers of the group.
5. Maybe there are special needs for people with medically acquired HCV? Litigation.

### PATIENT INFORMATION - SOME THINGS YOU MAY LIKE TO BE AWARE OF SO THAT YOU CAN TAKE CONTROL OF YOUR BODY

- Contributed by David Single

The following information can be used as a guide. Remember your doctor is a resource person, there to help you.

# Advise your doctor on existing medications that you are taking. (It may be wise to take the medications along with you as this will prompt the doctor to check the script if necessary.)

# Always be wary of starting or stopping medications. Some medications cause serious side effects if stopped suddenly (e.g. Prednisone, Serepax, Tryptanol). Check with your doctor (or even a second one of you wish).

# You can always ask your doctor to read out the relevant parts of MIMS so that you know the possible side effects, reactions with other medications, age related dosage and starting/stopping precautions.

#Talk to other patients. You are usually not the first or last person with your condition or variation of medical problem. Ask your doctor for information and self help groups available in your area. Sometimes you have to persevere. However, you have a right not to share if you are asked so exercise that if you need your privacy.

## *IN HOSPITAL*

# You do not need to leave the examination or hospital room when your partner, spouse or child is being examined or interviewed, unless your partner prefers you to leave. It is always better if the patient tells the doctor he/she prefers the partner to be present. If doctors and nurses are performing a 'sterile procedure' with masks and gowns, you may be able to be present wearing the same type of protection. Do not interfere with the examination or keep talking while staff are trying to concentrate.

# Try to have your partner or a tape recorder with you when visiting specialist doctors. Your partner will hear, remember and prompt any discussion with your doctor that you may not hear when being examined, treated or while dressing. When ill and under stress, you will be amazed at what basic facts you have forgotten to ask.

# In hospital you have rights as a patient. All staff must treat patients with "Universal Precautions" i.e. treat all patients as if they are infectious and should not need to label their rooms. Nursing and medical staff must wash their hands before treating or examining any patient. Insist on this to protect you and the staff.

# If you are "Neutropenic" (a neutrophil count less than 1000), then a strict handwashing routine must be observed by staff, family and visitors, and you, the patient. If you are neutropenic and have a fever at/or above 39 degrees Celsius, then you should be in a single bed room to prevent infectious complications.

# Remember the Intern and Resident staff are not as learned as the Registrars and Specialists. If you have doubts about their information, ask to see someone more senior. You should attempt and succeed at being fully informed about your condition. It's your life and you have to manage it 24 hours a day.

## *BLOOD TESTS*

# You can find a GP who will take blood in the surgery for blood testing by pathology. There should be no need for referrals to Pathologists, or for you to run all over town, and the tests can be classed MEDICARE PATIENT only, with no Gap payment by you if you ask the doctor.

# Ask to have a copy of all test results. You can keep a file. They can be lost in hospitals and when you change doctors.

# Know what your normal results are and what are the normal values for your age and gender. Remember small changes are usually not significant - trends are more important.

# Regular tests should include FBC (full blood count) and LFT (liver function tests) and the time between tests usually depends on how well you are. Normally, LFT's can go up and down a bit without meaning anything specific.

# Be aware that some medications cause short term changes to normal blood test values. You should tell your doctor your medications before blood testing. Most chemotherapy will affect White Cell and Platelet counts in your blood tests. Talk to your doctor. You will be amazed at what low counts the body can survive on!

## *GENERAL*

Finally, remember that you are part of the medical team, trying to do the best for you and your body. Your doctor has the information - you will need to give him/her the facts and ask the right questions.

## LIVING WITH HEPATITIS C AND INTERFERON

- Genevieve Latchford

For those of us who are not prepared to become victims of our disease there are certain lifestyle changes that can be made to improve health. For me it meant making changes to my diet and my social life.

When I found I qualified for the Interferon program I was in turmoil. I would be putting a drug into my drug free body and I wanted to be in control over what was happening. I felt it to be important to be as healthy as I could.

### - Practicing Relaxation Techniques -

I found by calming my overactive mind and body down, I could leave room for ACCEPTING what was happening to me and to think about taking some POSITIVE steps. I think you are more likely to get better if you *think* you are getting better and the Interferon will work better for you if you *accept* taking it instead of fighting it.

There are many relaxation tapes available and plugging yourself into one for 5 minutes a day is a good way to get started.

### - Diet -

When it comes to diet, there is always so much information that it can be confusing. In my experience I have found that instead of loading myself up with vitamins, pills and potions (an adding onto process), that a taking away of the more harmful things is more beneficial where the liver is concerned. I would like to say here that everyone is different and a visit to your Naturopath, Macrobiotic or Shiatsu practitioner, or Oriental medicine practitioner would be of benefit. The idea is to *strengthen* your immune system and *nourish* the liver.

I found by eating a diet that is light, fresh and colourful and contains variety in both selection of foods and styles of food preparation to be helpful.

To aid healthy functioning the foods to be avoided or restricted are:- all animal meats except occasional non-fat white meat fish; tropical fruits and juices (High sugar content). Use spices sparingly and ALCOHOL, coffee and tea are best avoided. So are foods containing chemicals and preservatives.

Eat lots of:

GRAINS e.g. rice, barley and millet.

SOUPS e.g. miso soup has cleaning and detoxifying properties.

VEGETABLES, hard leafy greens on a daily basis e.g. kale, collard, mustard greens. Broccoli and carrots are also good.

BEANS - Tempeh is beneficial.

FISH and SEAFOOD in moderation.

SEEDS AND NUT BUTTERS - all have a high oil content so not too many.

FRUIT - restricted and eat cooked, locally grown and in season.

SWEETENERS - Barley malt or brown rice syrup.

SEASONINGS - Fermented foods such as tamari soy sauce and miso. Salt and salty seasonings should be mild.

BEVERAGES - Barley tea, Bancha tea, dandelion coffee; carrot and celery juice in small amounts.

On the whole the liver and gall bladder can be kept healthy by avoiding overeating and refraining from eating for at least 3 hours before sleep, and chewing very, very well.

### - Exercising -

I find this in moderation gives me energy and a good mental outlook. Take notice of your body and rest when you need to. Swimming, walking, yoga and tai-chi are some suggestions.

May I suggest to those who have difficulties giving up alcohol that sitting in on an Alcoholics Anonymous meeting may be helpful. Giving up drinking and drugs doesn't mean you have to give up having fun.

By making a few changes you may find the path to a healthy and happy life. The choice is yours. I have been taking Interferon for the past eleven months and am on the two year program.

#### REFERENCES:

The Macrobiotic Way of Zen Shiatsu by David Sergei.

## NOTES

### 1. NATUROPATHY

We have been told that a Dr. Tony Goh at Chatswood (411 5011) is interested in treating Hepatitis C, using herbs.

We have also been told by many naturopaths that ST MARYS THISTLE is very beneficial. It is available as PROL 7000, to be taken 3 times a day.

Some of our members are finding that they are not feeling as tired when they take Vitamin C (only up to 2,000 mg daily as calcium or sodium ascorbate).

2. STATISTICS gathered by the Department of Health show that Hepatitis C is four times more common than Aids and is now the most common chronic infectious disease in our community. In the 6 months to the end of June, nearly 2,000 cases were reported in NSW.

### 3. GOVERNMENT APPROACHES

Specialists in liver diseases have been lobbying the government to try and get more appropriate services for Hepatitis sufferers, to just be met with "No" and they feel very frustrated, while the Aids facilities continue to grow (largely because they are in part federally funded). We have had one direct knock back in our approach to the Minister in asking for a Project Officer to coordinate efforts for Hepatitis C sufferers, a nurse educator to raise the general knowledge in hospitals, and some financial backing. A second approach was met more cordially, and as yet we have not been refused, but have not been promised anything either. We are still continuing.

### 4. AVAILABILITY OF INTERFERON

We are still hoping for Interferon to be licensed shortly, so that it is available for those not on the experimental programmes, and maybe closer to being made available at a reduced cost. There will be several trials of Interferon treatment for Hepatitis C continuing throughout 1993 and probably well into 1994, so that access to treatment in Sydney, Newcastle and Wollongong should be reasonably liberal.

### 5. RESEARCH

Scientific research is advancing extremely rapidly. We now know that there are multiple strains of the virus, some of which may be more or less susceptible to treatment. We have also learned confidently that the minority of patients who have a long term response to Interferon treatment are, in the substantial majority of cases, almost certainly cured of their viral infection.



## OUR OWN RESEARCH

**Attention: Interferon users (or past users).**

We would like anyone out there who has been on, or is currently on an Interferon programme, to write a few words on:

1. How has it affected you?
2. What dosage?
3. Length of time on programme?
4. Side effects (if any)-both during and after?
5. Once off the programme, did you LFT's stay improved?
6. Did you have a better feeling of well being after the programme?

We look forward to hearing from you, please send you reply to:-

"Stuart",  
Hepatitis Support Group,  
PO Box 98  
WESTMEAD NSW 2145

as soon as you can and we shall publish the results in the next newsletter. We want to do this as a way of sharing and maybe making a more realistic list of side effects than just "flu like" symptoms.

## ADVERTISEMENTS

### **HELP NEEDED FOR FUND-RAISING.**

Anyone able to help with fund raising for the Group, please call Sharlene or Steven on 718 7121 at home after 6pm, or Sharlene at work on 399 4208.

We have lollies and nuts for Christmas, 200 and 300 gms for \$2 & \$3 each. Order forms will be available from 21st September from Sharlene.

### **PRINTING FACILITIES?**

Is there any one out there who has access to printing facilities? If so, please contact Bernard Eddy on 365 3224.

### **PHONE ROSTER**

We need more volunteers for the phone roster please, particularly during the day. If you can give 1/2 a day per week to stay at the phone, even though you may only get one or two calls, please contact Audrey - 584 2421.