HEPATITIS C COUNCIL OF NSW

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Preface - A Brief History

The identification of the hepatitis C virus (HCV) in 1988 established a new era in the scientific understanding of hepatitis C, previously known as Non-A/Non-B hepatitis. In stark contrast though, individual people affected still faced confusion and ignorance regarding their condition. A need for community-wide information and support was and remains clearly visible. **Professor Geoffrey Farrell** of Westmead Hospital recognised this need. He supported the setting-up of a patient support group that inaugurated in November 1991 as the NSW Hepatitis C Support Group. The primary purpose of this group was to provide support for people with HCV, and to represent the interests of such people within the broader community. A toll-free 008 support line involving a network of metropolitan and non-metropolitan volunteer telephone counsellors was established.

The group became incorporated in February 1993, as the **Australian Hepatitis C Support Group**, soon gaining the status of a registered charity. While remaining committed to client support services, the group increasingly began to address public and peer education. The focus of the organisation had begun to include Federal issues as well, such as access to Interferon treatment and social security pensions. Liaison with peer health and welfare based agencies had also increased considerably.

With federal funding submissions rejected, the group could not function on a national level, and in July 1994, the Australian Hepatitis C Support Group reformed as **The Hepatitis C Council of NSW**, moving to its first offices at Belmore St, Surry Hills in Sydney.

1994 also marked the **NSW Health Department's** formal acknowledgment of the Hepatitis C Council's role by providing ongoing funding for the provision of counselling and support services. This marked the beginning of a shared commitment to address HCV need within the NSW community.

In October 1994, NSW Health convened a state **HCV Taskforce**, aimed at identifying gaps in HCV healthcare provision, and proposing strategies that would meet such gaps. The Hepatitis C Council was invited to sit on this taskforce along with other community-based groups and government departments.

In December 1994, we relocated to more suitable office accommodation at Crown St, Surry Hills. In February 1995, NSW Health approved further funding as a contribution to our core operating costs. This has enabled us to provide a more professional and effective service.

Australian Hepatitis C Support Group Inc.

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Newsletter No. 7 **December 1993**

Update from America

Geoffrey C Farrell, MD, FRACP

Robert W. Storr Professor of Hepatic Medicine

The Annual Scientific Meeting of the American Association for the Study of the Liver covered many advances in knowledge about hepatitis C. An important aspect is the contribution of hepatitis C infection to chronic liver disease. An extensive survey conducted by the United States Centres for Disease Control (Atlanta, Georgia) found that chronic viral hepatitis is now equal to, or more important than alcohol abuse as a cause of cirrhosis in the United States. Overall, 44% of cases of chronic liver disease were attributable to hepatitis C compared with 39% to alcohol abuse and 14% to hepatitis B. Another interesting statistic is the relative importance of chronic viral hepatitis and AIDS (HIV infection) as a cause of death. In the United States, it is now estimated that the annual death rate from HIV is 16,000, from HBV 5,000 and from HCV 8,000. There is no reason to suspect that the proportion of cases is any different in Australia, except that HIV infection is probably less prevalent here and HCV infection at least as prevalent as in the USA.

There are several interesting new facets about treatment. More intensive early treatment (high dose interferon) seems to make no difference, unless 10 million unit doses are used. This gives rise to a higher long-term response rate but one-third of patients cannot tolerate this dose due to severe side-effects, so it doesn't appear to be a very good option. On the other hand, at least three papers described more prolonged treatment (12 months versus 6 months), including a study of 2,000 patients in Italy. These studies all show better long-term results (generally a long-term response rate of 35-40%) amongst those treated for 12 months versus 15-25% long-term response rate in those treated for six months.

There were two studies of ribavirin. My impression is that when this agent is used on its own the results have been disappointing. Many patients have improved their liver enzymes but the hepatitis C virus seems to persist. On the other hand, two studies of combined treatment with interferon and ribavirin seemed to show very encouraging results, although the numbers treated were small. There were also three small studies on the effects of increased iron concentration in the liver and response to interferon. These studies seem to find that liver iron content is higher amongst people who don't respond, but this is probably not of practical value because when the iron was removed (by venesection) the subsequent response to a further course of interferon was not beneficial in the long-term.

HEALTHY CARRIER STATE - AN UPDATE

(John Mackenzie)

Two recent articles published in the Lancet have highlighted the disparate stance now being taken by researchers over the idea of the existence of "true healthy carriers of HCV" (i.e. individuals who have persistent antibodies to the hepatitis C virus (anti-HCV), yet who appear to have no symptoms or signs of liver disease. Recent research which challenges this idea obviously has important implications for the clinical management of patients.

In *Lancet* (20 Feb 93) a group of Italian researchers published findings which "indicate persistent hepatitis C viraemia is not invariably associated with liver disease" (see our Newsletter No. 6) One theoretical hypothesis suggests that all four subjects may have been infected by a non-virulent strain, but as well, this study was limited to only four patients over three years, and the span of the illness from initial infection was not indicated.

In another Italian study in *Lancet* (19 Sept 92) liver biopsy samples were taken from 23 symptom free HCV patients (16 of whom had normal ALT values) to assess the prevalence of liver disease and to see whether tests for anti-HCV (Elisa-2 & Riba-2 and HCV-RNA (PCA) correlated with pathological findings. The biopsies disclosed 'features of chronic liver disease in 16 cases, including 10 with chronic persistent hepatitis (6 normal and 4 abnormal ALT) 5 with chronic active hepatitis (2 normal and 3 abnormal ALT) and 1 with cirrhosis (normal ALT). The remaining 7 patients had normal liver histology.' None of the 23 patients had presented for signs of liver disease at physical examination.

These results indicate that symptom free HCV patients 'frequently have chronic hepatitis'. Further, as is now commonly accepted, ALT values are not reliable predictors of liver pathology, nor were tests for antibodies for HCV. However their research indicated that the PCR test results 'were significantly associated with liver histology'. (note: In Australia, PCR is limited to use as a research tool only as it is difficult to do reliably and is extremely expensive.)

In *The Medical Journal of Australia*, 16 August 93, Dr. Nick Crofts et al who were researching the epidemiology of infection with HCV among IV drug injectors stated that their findings support a 'relationship between PCR positivity and a poor long term outcome in terms of disease progression, providing no support for the concept of a "healthy carrier state" in chronic hepatitis C infection.' At the recent National Symposium on Hepatitis C in Melbourne, leading Australian and international researchers and clinicians, all stated that the concept of a "healthy carrier state" could no longer be readily accepted. In a paper given by Dr Paul Desmond of St. Vincents, Melbourne, a study conducted with 331 patients of which 126 had liver biopsies found that all 126 had evidence of liver disease. 67% had chronic hepatitis and 33% had

cirrhosis. There was no difference in median ALT level between those with cirrhosis and chronic hepatitis. Biopsy performed on 8 patients with persistently normal liver function tests showed chronic hepatitis in all.'

As the balance of research shifts to oppose the concept of a "healthy carrier state" it is now important that people with chronic hepatitis C should assess the value of this research in making lifestyle and treatment-seeking decisions (see also comments by Professor Farrell in Newsletter No 6 advocating vaccination against Hepatitis B for HCV patients). Further as an organisation we should question the use and value of ALT levels as a criteria for limiting entrance to drug trials.

Finally, such research should add further discredit to those health officials who would still seek to play down the true debilitating nature of this disease.

NEWS AND NOTES

This last three months has been a period of considerable activity for the Group right round Australia as at last HCV is getting more of the attention it deserves from health authorities and the media.

Probably of most importance was the delivery at the beginning of November, of the **Report on Hepatitis C from the Working Party convened by the National Health & Medical Research Centre** in Canberra to the meeting of state and federal health ministers.

It is 36 pages long (without references).

Amongst other things it states:

S1.2 "Additional studies are needed to define more precisely the infection status of patients and the likelihood of disease progression. Guidelines on diagnostic testing strategies and interpretation of laboratory results are clearly required."

"The reasons for the variability in disease severity are largely unknown. However, there are least 6 major strains in genotypes of HCV, and it is thought that some are more pathogenic than others. It is also believed that repeat infection of a carrier with a different strain will exacerbate underlying liver disease. It is not known which strains predominate in Australia and the relative susceptibilities of various ethic groups and the consequences of HCV are also unknown."

S1.3 "Screening: Prospective donors who are + for HCV antibody should be deferred from donating. There should be selective testing of others in the community as clinically indicated." (In 4.1.7 these are defined as patients with a clinical illness consistent with hepatitis; anyone with a history of injecting drug use; anyone who has received many transfusions of blood or blood products; renal dialysis patients; prospective organ or bone marrow donors; patients attending STD clinics; patients with a history of imprisonment and patients with a tattoo."

S1.4 "Therapy: Normal immune globulin is of no benefit in post exposure prophylaxis or the management of this disease. The role of Interferon is uncertain in acute hepatitis C.

6.1.2. "It is recommended that ongoing prospective studies be conducted of outcome in Australian patients with chronic HCV, including those treated with anti-viral therapy."

6.1.3. It is recommended that centres involved in managing hepatitis C gather data systematically to allow the natural history to be defined: (i.e. a central registry and regular analysis)

7.1.1. "It is recommended that education and counselling programmes be established for:

a. members of high risk groups, including enhancement of current education strategies for injecting drug users;

b. health care workers and others occupationally at potential risk

c. members of professions potentially involved in transmission (eg surgeons, dentists, tattooists, acupuncturists;

d. those diagnosed as anti-HCV positive;

e. undergraduate and postgraduate medical and paramedical students;

f. prostitutes, and

g. the general community.

8.5.1 "It is recommended that continued review be conducted of the data on the efficiency of treatment regimes such as interferon alpha, ribavirin and other antiviral or immunomodulatory therapies in chronic HCV. And, also a detailed cost-effective analysis of the role of interferon alpha in the treatment of HCV."

Media watch and contacts have been ably led by John Mackenzie who has done a sterling job in keeping pressure on radio stations particularly to broadcast latest developments as they have come out from the Melbourne Symposium and so on. This has resulted in many enquiries for information from all states (except perhaps Tasmania) and some good contacts.

★★★★★

South Australia, Canberra and Brisbane will have held their inaugural meeting to establish a state branch of the national support group by the time this goes to press. We wish them well.

★★★★★

Our patron, Professor Geoffrey Farrell, has been honoured with the conferring of a special Professorship in Liver Research. Congratulations!

★★★★★

Western Australia and the NSW Branches are now usually asked to comment on any government publications on HCV - however, we were not asked for any input into the federal working party!

The President, Warren Wright, is hopeful of obtaining a meeting with Senator Richardson, Health Minister in Canberra, at the beginning of December, to discuss our needs. Any pressure you can bring on him through your federal member would be good value - numbers of people from all round Australia jumping up and down, do have a helpful impact - it makes the ground shake and politicians feel shaky!

★★★★★

If you are not a financial member, you must renew now!

$25 or $10 (Pension No. Please)

$15 Newsletter only

Reprint from earlier newsletter on Buist's recommendations for vitamin and herb intake for Hepatitis C patients.

Vitamins: 30 mcg beta carotene daily

1-2000 mcg Vitamin C one or two times daily (taken as sodium or calcium ascorbate if you are inclined to acidity)

500 international units Vitamin E

Foods: Kyolic Garlic - 5 ml per day

Foods high in sulphur amino acids and methionine (fish, eggs and lentils)

Anti-viral herbs: Phyllanthus Amarus and Hypericum Perforatum (St. John's Wort) Use one OR the other.

Anti-inflammatory herbs Silibum Marianum (St. Mary's Thistle)or

Bupleurum Falcatum (to reduce the inflammation and pain in the liver)

Ethiopian Proverb

"When spider webs unite, they can tie down a lion" This saying underlines how important it is for us all the unite to get some attention for Hepatitis C from Health Departments. The letters to members of parliament were an example of this, and I am sure were the reason why we finally were granted an interview with the head honchos of the N.S.W. Health Department. Pressure certainly works, as our friends in Western Australia found out. To get an interview with the Health Department there, they not only wrote, but when they received no reply, they faxed him every day. Look what they got - $250,000 for research into HCV and the user community!

STOP PRESS

All three applications for federal funding were rejected. Please seek the assistance of your local federal member to find out the best ways of achieving funding for a secretariat for us.

NSW will have a funded full time coordinatting early next year under the Non Government Organisations grant!

HCV IN THE USA (Cheryl Burman)

Dr Miriam Alter, a leading epidemiologist studying Hiv in the USA, spoke to medical professionals at Prince of Wales Hospital in Sydney in October. Statistics she disclosed alerted those at the lecture to the serious nature of the disease.

She firstly discussed the various testing procedures presently available which unfortunately still do not detect 10% of sufferers, give frequent false positives on first testing and no way to distinguish between acute and chronic phases of the disease. Hopefully the third generation test to be introduced in the near future should be more reliable.

In the USA, 21% of those suffering from hepatitus have HCV.

Sexual risks were greatly increased by promiscuous behaviour, syphilius and acts involving trauma and blood.

Dr Alter then referred to a USA study in which patients were monitored for between 9 and 49 months fom the preseumed onset of infection. 68% had consistently raised ALT levels and were classified as having chronic hepatitis. However biopsies seemed a more accurate predictor of prognosis. Those acquiring HCV through blood transfusions (Because of greater viral load received) had a greater likelihood of developing chronic active hepatitis.

Reference: The Natural History of Community Acquired Hepatitis C in the USA, New England J. Medicine, V 327, No 27, Dec 31, 1992 (1899-1904)

NOTE from the NSW PUBLIC HEALTH BULLETIN

(Vol 4 No. 10, October 93)

"Since clinical hepatitis A may be more severe in persons with chronic disease due to hepatitis viruses or other aetiologies, use of Hepatitis A vaccine in these persons may be considered. The side effects are usually mild and confined to the first few days after immunisation. Common side effects are fever, malaise, fatigue, headaches, nausea and loss of appetite." (Editor's note: "What's new?")

Two 1ml doses of vaccine are given 2-4 weeks apart by intramuscular injection in the upper arm. The antibody response may be impaired in people whose immune system is compromised, such as HIV+ individuals. A booster dose between 6 and 12 months after the primary course results in more persistent following the booster dose is unknown."

Also from the same publication: Notifications of Infectious disease in NSW for the twelve months September 92 to September 93.

AIDS	200
HIV	407
HEPATITIS	425
HEPATITIS B	2,500
HEPATITIS C	3,787

From NEWS, in NATURE,

Vol 362, March 93

In Japan the Hayashibara Pharmaceutical Company has been awaiting aproval for its technique of mass producing interferon in cancer cells in millions of mice. In this way, it hopes to corner the huge market for Interferon in Japan which has 1.5 million carriers of the HCV virus, a far larger proportion of the population than in the USA or Europe. Interferon treatment now accounts for 1% of the total medical bills in Japan, as tens of thousands with evidence of active chronic hepatitis in liver biopsies are allowed interferon treatment.

Japanese hospitals have a strong incentive for prescribing expensive interferon treatment, as they buy and sell their own drugs and can make profits.

The prevalence of Hepatistis C in Japan may be due in part to the common practice several decades ago in reusing needles in mass vaccination programmes, resulting in 10% of patients receiving blood transfusions being infected with the virus because of the high incidence of HCV among blood donors.

COMMENT ON ARTICLE IN S.M.H. (PAGE 7 9/8/93)

his article reported Farrell as saying that in N.S.W. there has been a political antithesis towards Hepatitis C disease in that the Health Department is refusing to warn people who were at risk of contracting the disease fprior to 1990. Dr. Sue Morey, Chief Health Officer of the Department denied this, saying the department had done everything it could, and continued to make more untrue statements, such as

1. that they don't fund special diseases (they do fund HIV, on a one-to-one basis with the Commonwealth; and also cancer for example)
2. that testing of "at risk" persons meant they had to go to Westmead
3. that there was no treatment, and that it still had to be defined which people were helped by interferon
4. that Professor Farrell was only out to get major funds for his personal research.

The Group has written letters to the Editor of the S.M.H. and also to Dr. Morey about the untruth of her statements and her scurrilous vilification of Professor Farrell. Other letters in support of what he has said have been written to the Department by hepatologists in areas such as the Hunter, the Central Area Health Service and the Southern Area Health Service.

As the Department tries to avoid its commitments by putting all responsibility for how health resources are spent in each area on to that area's Chief Executive Officer, it is important that every member of our Group should not only again make contact with their local member stressing how illadvised, heartless and short sighted the Department is, but also contact their Health Area Executive Officer to ask for more resources to be spent on HCV in their area. We need facilities for counselling by counsellors trained in HCV issues, both post testing and further into the illness, and for both the patient and their 'significant others', warnings to those at risk of having contracted HCV, more availability of hepatologist health care for country areas, and listing of Interferon on the Pharmaceutical Benefits Schedule so that it was affordable for patients who were not eligible for inclusion in the Australian studies.

In states such as Queensland, South Australia, Tasmania and Victoria, where governments seem to be doing nothing, members really have to start from scratch to try and get them to pay attention to Hepatitis C, stressing that it is 5 times more prevalent than AIDS, and that it is a potentially fatal disease which has major expense ramifications in the future.

In Western Australia, the Government, thanks to pressure from the Group members over there, is running press and TV advertisements, indicating those who may be at risk and offering diagnostic facilities and counselling for those who come forward.

SOME COMMON ANXIETIES WE SHARE

At a recent meeting of the Group held at Westmead, led by Cecilia Raffo, we shared our experiences of anxieties and concerns we had faced, or were currently facing, in coming to terms with our disease.

Some of these were expressed as:

- Worry about pinpointing the source of the infection - its implications for social responsibility
- Lack of education in the community, leading to a feeling of alienation
- Lack of information among medical personnel - leading to confusion and increased anxiety
- Trivialisation of the disease and a feeling of patronage, by medical personnel, leading to alienation and increased anxiety
- Concerns about disclosure and the effect this may have on relationships and job acceptance
- Discrimination in the work place (particularly loss of job)
- Changes in lifestyle, forcing us to evaluate our lives so that we have to put our health first.
- Giving up - alcohol, being able to keep up with everyone else, frequency of sex because of being too tired, career prospects, financial security
- Anxiety about treatments available - interferon and the side effects - medical procedures & biopsies - how to evaluate alternative treatments - the very lack of a positive "cure"
- Anxiety about the burden being placed on your partner and concern for him/her
- Being unable to get any respite from either the disease, or the worry about what it implies for the future
- The stress of keeping up what you are doing plus wondering how long you can keep it up

Some techniques which had been found to be helpful in combating these worries were:

* For ignorance – more accessible information

* For alienation – availability of good counselling to reaffirm one's validity and help maintain self esteem; volunteering service

* For depression – regular exercise as part of a routine; laughter and comedy, a positive outlook; God; breathing techniques, yoga, meditation; Quest for Life

* For fatigue – relaxation tapes; cat naps; exercise; good nutrition; reike and massage

* For frustration – changing one's attitudes to be more forgiving of oneself; creative visualisation; positive affirmation

* For financial anxieties – a clearer understanding of the DSS pension net for physical disability "employee friendly" work practices

* For family – the availability of counselling services to help sort out any relationship problems which may arise, and to give an opportunity for the partner to vent their concerns/frustrations

Any comments anyone has about this list would be very helpful, as it may be useful as a basis for us to talk to community groups about HCV and what it means to us. Please contact Audrey Lamb, c/- P.O. Box 98, Westmead 2145

EVALUATING OTHER "CURES"

(Adapted from the Arthritis Self Help Course of Dr. Kate Lorig, Stanford Arthritis Centre, Stanford University, U.S.A.)

If you are considering a specific form of alternative therapy, there are some important questions you should ask.

1. Is proof by testimonials (e.g. Mr. Smith says it works) or by scientific research? (and if the latter, was a "control group" used?) Observations of single cases, such as those reported in testimonials, simply do not give enough information to tell whether treatments really work or would work for others. Clinical trials help us sort out the effects of the treatment from psychological influences, coincidence and other factors.

A clinical trial is an experiment in which one group of people gets treatment (Group A) a similar group receives no treatment or a "traditional" (long standing treatment (Group B), and the results for the two groups are compared. If Group A does better than Group B the conclusion is that the new treatment helps. But if roughly the same proportion of people improve in both groups, the conclusion is that the new treatment has no effect or at least no greater effect than the traditional treatment.

2. Were people who used the treatment similar to you? For example, was their arthritis less severe, were they younger, were they leading a healthier lifestyle in such areas as nutrition and exercise?

3. Could anything else have caused the results being claimed? For example, could it have been a coincidence, and the belief that some treatment will help can have a "positive thinking" influence on someone's feelings - the placebo effect.

4. Were the results of research published in a reputable journal? Editors of scientific journals usually check articles submitted on research into treatments very carefully in terms of the soundness of research. Newspapers or popular magazines do not necessarily do such careful checking.

5. Does a diet eliminate any basic food or nutrient? For example, if the carbohydrate food was eliminated, a diet may harm your health. Reputable dietary guidelines prepared by government health departments recommend having food from all food groups.

6. Does a diet stress only a few foods? If it does you will have little variety in your meals, leading to an unbalanced diet and possible harm to your health.

7. Can you afford the treatment?

8. Are you willing to go to the trouble/expense?

9. Can you think of possible dangers/harm?

REPORT ON THE NATIONAL HCV SUPPORT GROUP CONFERENCE

(held Melbourne, October 93)
by Ali Marsh, President W.A.

As is clear from these newsletters (and a number of other activities you may not be aware of) a very active and efficient national body already exists: the Australian Hepatitis C Support Group. The Group's existence is due to the dedication of a small number of individuals who have put enormous amounts of unpaid time and energy into establishing and maintaining the Group. However, as with all initiative which are established quickly out of an urgent need, the time comes for clarifying, streamlining and forward planning.

This report concerns the outcome of such an activity.

The Hepatitis C Symposium held in Melbourne on October 8 1993 (and for which we gratefully acknowledge the contribution of Dr. Katrina Watson, the organiser, in allowing us 6 representatives at half price as Observers) was used as an opportunity for representatives of existing Hep C Support Groups and other people interested in establishing them to meet the next day and talk about how our national body can best operate.

It was agreed that a national body representative of state Hepatitis C Support Groups was essential and that its purpose should be to:

- Support state groups in their activities
- Coordinate national strategies and activities as regards media, influencing policy making, lobbying and promoting research
- Secure and disseminate federal funds to state groups on a needs and feasibility basis
- Facilitate communication between states.

It was also agreed in principle:

- To accept the existing Australian Hepatitis C Support Group as the national body
- To change the name to the Hepatitis C Council of Australia (HCCA)
- That the HCCA should be governed by a committee comprising two members from each state sub-committee
- That representatives from states without established support groups, or from support groups which are not sub-committees, could still participate in national body meetings but not have voting rights.
- That the basic legal compliance requirements for groups to become subcommittees of the national body would be discussed with groups (or potential groups) in each state.
- That membership fees be divided between the national body (to cover the cost of national newsletters etc) and the state subcommittees - the rate to be precisely determined.
- That state subcommittees could incorporate at a state level - such incorporation being thought to be necessary to obtain state funding.
- Joining the national Council as a subcommittee was to be encouraged because it ensured state representation at a national level, meant that states could access federal funding, and obtain help and support from the national body.

The above ideas were to be taken away and discussed with state committee members before final decisions were made. (Note: the complex issue of national decision-making also needs further discussion.)

It was also agreed that communication between state representatives would occur regularly via teleconference. The first teleconference is planned for late January 1994.

At the end of the day many important issues had not been discussed and were listed as agenda items for future teleconferences.

All told, the day was extremely beneficial. A number of important issues were discussed and clarified and plans were made to facilitate this process in the future. Some of the best things about the day were being able to put names to faces, talk to people face-to-face, and to sort out confusions and misunderstandings. The outcome has been increased respect for other members, an appreciation of their particular strengths, and the formation of a truly collaborative working relationship between people across Australia whose primary aim is to further the needs of the Hepatitis C infected and affected community.

Many thanks to the Melbourne Group who did a wonderful job making us feel welcome and hosting the meeting.

Interferon

Following the S.B.S. Date Line telecast recently, we had a phone call from a doctor who has been researching why some patients after surgery for cancer go on to recover completely and others die. His research has again pointed up the fact that cancer seems to develop from oxidation caused by the chemical processing of some input into our bodies.

Dr. Fitzherbert's concern was that Interferon gamma (immune interferon) is known to produce oxidation as it reacts and is broken down in the tissues, and he felt that patients put on Interferon should be aware of this as it could possibly be carcinogenic. (However interferon was first used to combat cancer.)

There are many different interferons. All interferons are polypeptides, however alfa interferon is a protein which is acid stable. Gamma interferon is a glycoprotein and is acid labile.

It is suggested that nitric oxide is produced during the action of gamma interferon, and has been shown to be mutagenic. This does not appear to be the case with alfa intron-A. However, Dr. Robert Buist suggests that whenever anyone is on interferon, they should be taking anti-oxidants (mainly C and E) as a precaution.

Dr. Fitzherbert points to the growing evidence that selenium is necessary for the uptake of these antioxidants, and suggests that Selenomethionine (100 - 200 mcg) should be taken daily to potentiate the intake of beta carotene and vitamin E, as our soils, and hence our crops and livestock are deficient in selenium.(Journal of Biological Chemistry, Vol 268, No 4, Feb 5 1993, p 2572-76, and Free Radical Biology & Medicine, Vol 14, pp 473-82, 1993) Dr. Buist also supports this.

Dr. Fitzherbert also points out the advantages of Zinc which, in small amounts, is an essential element in the development and function of the immune system. (Zinc is being used quite widely in trying to combat the effects of the HIV virus.)

Mind Power vs Drug Power

(Written by an unnamed Melbourne psychologist and printed in the Arthritis Update magazine, Vol 6 No1)

When I was a little boy the words mind power always gave me goose bumps. They conjured up pictures of a powerful man staring at someone unblinkingly and making them rise in the air,or a kind of combination between Ali Baba and his "Open Sesame" magic, and a regimental sergeant major who makes hundreds of men stand to attention looking like stuffed carp.

In the course of growing up, the little boy observed the stage "hypnotist" who made apparently normal people hop around and utter chicken noises, the aunt whose hernia was cured in one visit to a faith healer and Uri Geller who reduced the mystery of mind power to the unspeakably boring level of wrecking people's cutlery and watches.

Later, working as a psychologist, I saw what mind power really was when I observed many patients learn to live with incredible physical handicaps, and others climb out of the pit of mental confusion and despair,. I observed how other people were able to maintain active lives and a cheerful mood in the face of intractable pain. It became clear to me that there was more to mind power than levitating objects and bending spoons.

The systematic scientific study of mind power has shown that our thoughts are the "mother and father" of our feelings. That is to say: what we call our feelings are interpreted by our thoughts, and as a consequence of learning, the very thought can then trigger a feeling. Here is an example: I am not a good "sailor" i.e. I tend to get motion sickness. At one stage, the unpleasant experience of feeling and being sick led me to feeling nauseated even upon going aboard a stationary ship. In other words, the sights and smells of being aboard, even without the actual motion of the sea, were enough to awaken the memory (thought) of being sick, which triggered the dread (feeling) of the experience, which in triggered the nausea (sensation).

In time, I learned that anxiety also played a strong role in my anticipation. Overcoming the anxiety helped me overcome the negative anticipation. Interestingly, I also found out that being at the helm of a sailing craft, even in lively seas, seemed to protect me from motion sickness. This observation points to another factor of mind power: That of being in control over events in our lives.

How does all this apply to pain and illness?

The noxious sensation of pain or illness invariably puts our whole nervous system into a state of alarm. If this is a chronic condition we tend to be in a state of alarm much of the time. This is called illness-related stress. It is now well understood that chronic stress interferes with our attention, our concentration (hence it can mess up our short term memory) and our ability to sleep well. It can weaken our immune system and we become more vulnerable to infection. It can affect our stomach, bowel and bladder function. It causes abnormal muscle tension patterns and postural distortions, which can lead to additional pains in various muscle groups. And of course, it leads to mood states of irritability, despair and aggression and sometimes to chronic anxiety and depression. Sounds familiar?

Managing your stress better can be just as effective as a powerful analgesic. What is more, managing your stress will have no negative side effects on your metabolism and organs.

The issue of being in control which I mentioned earlier plays an important role in our lives. It means that we know many of the events, circumstances and behaviour which trigger off an episode of pain or "unwellness", and we have a number of strategies ready to avoid or minimise its intensity or duration. This is part of good stress management, as the fact of having some control over events reduces anxiety and hence the unpleasant effects of anxiety as described in the previous paragraph.

Managing your illness related stress condition therefore, is not an alternative to sensible medical and physical treatment, it is an obligatory treatment which needs to be undertaken at the same time as medical treatments.

Exercise & Relaxation

(Adapted from an article by physiotherapist Cherry Lang and published in National Haemophilia No 74 May 1993)

There is now a considerable amount of evidence indicating the negative effect of high stress levels on immunity and health in both healthy and "sick" populations. At the VII International Conference omn AIDS in Florence (1991) a number of papers were presented which demonstrated negative associations between stress and various measures of helth and immunity in people who are HIV positive.

Some people, on receiving a diagnosis of HIV embark on a programme of self-help by which they hope to maximise their health and well-being. Two strategies commonly used are exercise and relaxation, both of which are popular techniques for managing stress.

In general it seems that moderate regular exercise produces benefits in terms of cellular immunity, as well as a feeling of "well-being", Aerobic exercise produces improvements in immune functioning, as measured by increased T4 cell counts. The second is that it may help to buffer the effects of stress by reducing its immuno-suppressive impact – there is already evidence available supporting both these possibilities. The third benefit is improvement in cardio-vascular fitness, again also supported by research.

Relaxation offers a different range of benefits to exercise, but like exercise it has shown benefits in immune functioing in helthy people and in people with HIV. It appears that the degree of benefit is linked to the frequency of practice: in other words, knowing how to relax is not enough – it is actually doing it that counts. As with exercise, relaxation has also been shown to buffer the immunosuppressive effects of stress. It is most useful to learn a method of relaxation that can be carried out in a stressful situation rather than requiring you to lie down in a quiet room; relaxation then becomes much more a part of everyday life and a useful tool of coping with those situations. Other benefits of regular relaxation practice are a reduction in fatigue, and a reduction of pain where there are associated with chronic tension.

Have a happy, healthy Christmas and New Year season!!