

The Hep C Review

Winter Edition - June 1995

No. 11

FEDERAL BUDGET - 1995 HEPATITIS C GETS LIMITED \$\$

Marking a continuing commitment to preventative healthcare, the Federal Government is to launch a major effort on preventable disease with an additional \$85.6 million committed to new initiatives and existing immunization and screening programs.



Federal Minister for Health - Dr Carmen Lawrence announces \$3.8 million funding allocation for hepatitis C research, prevention and education.
- Photo courtesy of AUSPIC -

The Federal Minister for Health, Carmen Lawrence, in her 9 May press release, said the added emphasis on preventative healthcare would bring considerable benefits to Australians as

both patients and tax-payers.

"It's an old adage but true that an ounce of prevention is worth a pound of cure," Dr Lawrence said.

"We have achieved significant reductions in heart disease for example, by promoting measures such as giving up smoking and taking up exercise, but there is much more we can do.

"To this end, the 1995 Budget establishes Health Australia - an \$18 million three year program dedicated to finding new ways to reduce preventable disease and death.

"It will conduct community education campaigns and set the strategic direction for the Government on these issues, including legislative reform."

Among other new initiatives, \$3.8 million had been allocated over two years

for the prevention of hepatitis C.

"The funds will be used for research and education," Dr Lawrence said.

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"Tie a Yellow wristband 'round the old hep C tree"

Abridged from Alicia Larriera's article in the Sydney Morning Herald 29/5/95

Sydney's Royal Prince Alfred Hospital is breaching national infection control guidelines by tagging patients with yellow wristbands - often without their knowledge - to indicate they have an infection such as hepatitis C or HIV.

The chairman of the Australian National Council on AIDS, Dr Don Grimes, criticised the hospital's policy as unnecessary and "not particularly good infection control practice."

He went on to say "having an armband system .. would breed a false sense of security", adding that "in the hospital setting, every patient should be treated as if they are potentially infectious."

The head of the AIDS Council of NSW, Mr Don Baxter, who was unaware of the policy said he was shocked by the idea of patients being tagged and said it contradicted good infection control practice. The executive officer of the Hepatitis C Council of NSW, Mr Stuart Loveday, was equally critical.

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"The research will be used to improve our knowledge on hepatitis C which will help identify the risk factors and the rate at which the virus is spreading.

"The education effort will target health-care workers and people affected with hepatitis C to help curb the disease's transmission," the Minister added.

A spokesperson for the Minister confirmed the funds would lead to a better understanding of the recently identified virus.

Surveys in specific populations will lead to increased knowledge of the true level of HCV infection in Australia.

Education strategies will be developed at the national level to help prevent the ongoing spread of the virus, to inform those who are affected, and to educate health professionals.

The national educational strategies will complement appropriate education and prevention programs in the States and Territories.

In addition, the National Health and Medical Research Council (NH&MRC) will develop guidelines for the control of hepatitis C. They will include guidelines for the care of patients, and for laboratory diagnosis.

This initiative allows the Commonwealth to partially implement its responsibilities under the National Hepatitis C Action Plan which was endorsed by representatives of the various State Health Ministers in October 1994.

The dual aims of the National Action Plan are to minimise the transmission of hepatitis C, and to minimise the personal and social impact for those already infected.

[The Commonwealth allocation of \$3.8 million over the next two years represents the first committed hepatitis C funding from the Federal Government.

Community-based hepatitis C organisations look forward to further Commonwealth/State funding that will enable the National Action Plan to be effectively implemented, especially in regard to supporting the community-based groups that will play an important role in an overall health and welfare response.

In this regard, we look forward to a productive ongoing relationship with the Federal and State Health Ministers - Ed.]

EDITORIAL

The expression "rules are meant to be broken" is easily misused by rebels without causes.

A more useful expression might be "rules are inevitably broken". This is certainly the case where theory comes up against human practice. This is what is currently happening with infection control in our healthcare system.

Hospitals and doctors' surgeries are places where people with diseases come together for treatment. This will always involve a very small risk of cross infections, although the degree of risk will depend entirely on the standard of practice you receive.

Until universal infection control procedures were adopted, if you had an infectious or contagious disease, you were usually segregated away from everyone else. This was called 'barrier-nursing', a form of infection control which often made patients feel like lepers - when food on paper plates comes under the door you know people think you have more than bad breath.

It also didn't work very well because some people had transmissible diseases yet were put into ordinary wards because no-one knew they were infectious.

Universal infection control guidelines were adopted in order to provide more humane and effective care. With hep C, the basis of this strategy is simple. All body fluids possibly containing the virus must be prevented from entering another person's body. In general, this means more than just someone cuming inside you or eating off the same plate, it means your blood musn't enter their blood stream.

Whether in a factory or hospital casualty ward, the problem with universal precautions is that although they work really well on paper, they are difficult to put into practice.

The onus is on healthcare managers to maintain good standards. Workers must be well trained and have the resources and time to carry out the procedures correctly: ie. using autoclaves to sterilise equipment, using single-dose vials of anaesthetic drugs, never re-using needles or syringes,

only using screened blood products, using single use filters in breathing equipment, etc.

But everyone is human and to be human is to make the occasional mistake.

When staff forget or make mistakes, things don't always go wrong. Over time though, something will go wrong. When it does, we soon know about it - our daily papers have a field day.

What we ideally need is an infection control strategy that is really easy to carry out. Until then, we need to make the best of our current strategy.

Nobody believes the current situation is perfect. Our current universal infection control strategies have been exhaustively researched and tested, but maybe they can be improved to some extent.

In this regard, we learned this week that Royal Prince Alfred Hospital has 'improved' its infection control procedures.

Spokesperson for the hospital, Dr Roger Garsia, says that HCV should be seen as an airborne virus. Positive patients should be identified by a visible wristband. Staff can then take extra precautions to avoid contracting the virus. Staff can also ensure the patient is not overly exposed to people with other infectious conditions.

The problem with this 'improvement' is that we could see a return to barrier nursing.

If particular information is irrelevant, it must be kept confidential. NSW Health does not believe hepatitis C status is relevant in a general ward.

Within a patient's records, hep C status is clearly marked - as are all blood samples taken. Surgeons are able to take whatever precautions according to the patient's records.

This confidential information does not need to be publicly displayed. Doing so will not lead to better health outcomes for the healthcare worker or patient.

We implore health authorities - stop the tagging!

The Hepatitis C Council of NSW

is an independent community-based non-profit organisation providing information and support to people affected by HCV - see page 20.

Management Committee:

Cheryl Burman - President

Bernard Fisher - V. President

Richard Booker - Secretary

Anita Long - Treasurer

Rod Charls

John Mackenzie

Jeff Dwyer

Steve Hopper

Staff:

Stuart Loveday - Executive Officer

Paul Harvey - Senior Project Officer

(to be appointed) - Admin Assistant.

Auditors:

Bryan Rush & Co

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Individual contributions are welcomed. The views expressed therein are therefore not necessarily those of the Hep C Council of NSW.

Ph: 02 332 1599

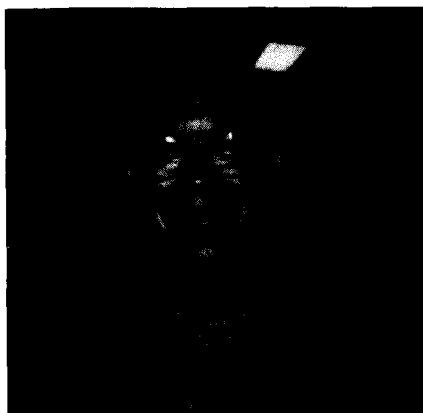
Fax: 02 332 1730

Support line: 1 800 803 990

345 Crown St, Surry Hills, 2010

PO Box 432, Darlinghurst, 2010

Getting to know your Council



Long-time Council and committee member, Bernard Fisher, who has played an important ongoing role in the development of your Council.

(ex)PRESIDENT'S REPORT

Community organisations play an increasingly acknowledged role in healthcare delivery. Such organisations are usually funded by State or Federal governments and are supported by the business sector and general public.

Unfortunately, community sector organisations are in direct competition with each other for limited government funding. Hence, you fundraising events are becoming increasingly sophisticated - Red Nose Day, Walk Against Want, Red Shield Appeal, Counter AID, Daffodil Day.

It is inevitable that as hepatitis C organisations fight for more government and fundraising money, the amount that goes to some other agencies will be reduced.

There are six state hepatitis C organisations who will soon form national federation.

After much effort from dedicated country members, the NSW Council has formally opened a Hunter branch office. We will be following soon with Illawarra and North Coast branches. We are planning the opening of three other rural branches.

Hep C organisations face many challenges. Two major challenges are our accessing increased funding, and making available to people with hep C, a greater range of community support services.

In this newsletter we feature the Commonwealth government's \$3.8 million hepatitis C funding package - money earmarked for research and prevention.

The addressing of these needs is valid and long overdue. We hope though, that this comparatively insignificant figure marks the beginning of a more comprehensive research and preventative funding package that enables the National Action Plan to be effectively implemented.

The recent Federal Budget failed to

mention any direct or cost-shared commonwealth financial support for community-based hepatitis C organisations.

This represents a serious error of judgement on behalf of the Federal Minister for Health, Dr Carmen Lawrence.

The National Action Plan is a product of a joint National Health and Medical Research Council (NHMRC) and Aus-

tralian Health Ministers Advisory Council (AHMAC) committee. The plan directly recommends, "the Commonwealth, States and Territories should assist appropriate community-based groups which address the needs of those people with hepatitis C."

Further still, if many other recommendations contained in the plan are to be suc-

cessfully implemented, health authorities must rely to some extent on community-based groups.

As well as support services, the community sector plays an acknowledged role in community education, prevention of transmission and patient management.

Quite possibly we will have a further funding campaign on our hands.

As previously mentioned though, as well as increased funding, people with hepatitis C need to be able to access all appropriate community resources.

The development of hepatitis C diagnostic, treatment and support services must therefore involve the use of existing services.

In the big picture, there is no sense in developing wide ranging support services for every new disease our society encounters. Where appropriate, we must share the wide range of community support services that already exist. These include community nursing, paramedical services, respite care, home shopping and meal services,



President's Report - continued

home maintenance, transport and personal care services, amongst others.

The Hepatitis C Council of NSW needs to research which existing services would appropriately service the needs of people with hep C related needs. We need to explore the best way such services can work together.

Many agencies would be hesitant to take on such a potentially large client group. This could possibly lead to an unbearable strain on their existing services.

With regard to these hesitations, if your Council is to ensure the best deal for you, we need to secure cooperation from the individual agencies and strategic support from key health and welfare bureaucrats.

The Council currently needs additional paid staff to enable all this. At a bare minimum, we need a full time staff of six. We could then adequately link up with other community support services, further develop our telephone information and support line, expand our postal information services, and further involve ourselves in the reviewing of health and welfare policy where it doesn't address hepatitis C related needs.

We will probably never have an adequate level of resources. Such funds will have been spent on propping up huge sporting events or fun parks, or the subsidising of private sector industries or the construction of tollways.

We therefore need to plan carefully. We need to consult widely before committing ourselves to action. In our strategic planning, we need to involve Council members, key individuals, our peer agencies and all appropriate government bodies.

We are currently drawing up a consultative framework from which our planning for the next few years will be drawn. This will involve you all.

This is my last President's Report. I recently applied for a paid position within the Council and was successful.

This necessitates my standing down as President. I now continue my work with the Council as your Senior Project Officer.

Paul Harvey

LETTERS to the editor

TO THE EDITOR

Just a note to thank you for your publication. Like other people, I was shocked to discover last year that I had hep C, and probably had contracted it as early as 1982 when I began using drugs.

I have a very confused perspective on hep C. For the last 6 years I have been [drug] 'free', so I guess I feel that I am a different person than the one who drugs and lived the complete 'inner city' lifestyle.

As a full-time student, my life is full and rich. Physically, I feel pretty good and except for the lapses of tiredness and stress, I do not appear to suffer too much from the the hep C, although not being much of a drinker and my eating well may be of value.

I wonder how many others are like me: basically feel pretty good and 'normal' but wonder what is going on inside and what lies ahead. Your *Hep C Review* is a great service and I look forward to being involved in the ACT Support Group.

Mr S.T.

TO THE EDITOR

I have enclosed a piece of writing as a submission for the *Hep C Review*.

Thanks for the interesting and informative news I received in the latest *Review*. It would really interest me if there was some information about how the virus could be passed on from pregnant mother to baby.

Ms J.S.

TO THE EDITOR

In September 1994, after blood tests it was confirmed that I had contracted hepatitis C, the cause being two blood transfusions - one in 1986, the other in 1987 when I had both hips replaced.

The blood tests show I am hepatitis C positive.

I joined the Hep C Council in March 1995 and found the *Hep C Review* very interesting, particularly the article on vaccinations (10, 17).

I wonder, if you could answer a few

questions for me?

On reading the article on vaccinations, would I be correct in saying that being HCV positive, I do not need to be vaccinated for heps A or B?

I have low iron levels in my blood, yet after many tests, the doctors do not know why. Would you know if other persons with hep C suffer from low iron levels?

Would you know of anybody getting compensation for contracting hep C through a blood transfusion in a hospital.

I hope my requests are not too much trouble.

Mr MB
Hornsby

(for a response, see page 17)

TO THE EDITOR

I was diagnosed HCV positive 2 years ago. I am currently on the methadone program at Cambelltown Hospital.

During a consultation with my counsellor, I discovered that a large percentage of clients at this particular clinic are also HCV positive. I then mentioned to her that I would like to start up a support group out here in south western Sydney. Problem is, I'm not quite sure how to start.

As far as my doctor and I have been able to work out, I may have had the virus for at least 12 years (diagnosed with nonA/B hepatitis in 1984).

I have read just about everything ever written on HCV, and of course, I feel I have first hand knowledge of how debilitating this virus can be. But is it enough simply to read up on the condition?

Perhaps there is already a support group operating out here? If so, no one seems to know about it.

I believe there is a great need for such a group in this area and I would really love to get more involved. But I also would want to do it the right way. Any information you could pass on would be greatly appreciated.

The director of the methadone clinic has told me I can put up signs the

clinic. That's a great place to begin, but do I need qualifications?

Thank you for your time in reading this letter. I'm very much looking forward to your reply.

**Ms KC
Woodbine**

[Certainly the Council is interested in initiating local support services. Anyone else interested in facilitating peer support group meetings should contact Paul, at the Hep C Council, on 332 1853 - Ed.]

To the Editor,

I have recently gone on Interferon and three months into treatment, my liver function tests have returned pretty well to normal.

This is great news for me but I am a little concerned about one thing - the amount of seminal fluid I normally produce has been reduced by about half. I wonder if anyone else has experienced this?

My doctors don't know how to explain this, and this leaves me feeling anxious. For instance, if in my case, this is a side effect of Interferon, will it be permanent?

Perhaps you could find out about this.

**Mr PM
Petersham**

To the Editor,

I'm a man who was diagnosed with HCV some 18 months ago and am currently undergoing Interferon treatment. I also recently joined the Council, receiving your information pack and recent newsletters today.

When I read the 'Letters to the Editor' section in the number 9 edition, I saw the letter from Ms R.E. concerning her problems experienced in trying to develop intimate relationships. This has also been a major concern of mine, and I would happily participate in a 'dating/contact' feature as mentioned in that edition.

Finally, I am glad to be a member of the Council and greatly appreciate your efforts within the community. It is reassuring to know there is an organisation that is doing its best for HCV sufferers and their concerns. Keep up the good work!

Mr DP

To the Editor,

Did you know that at a major central

Sydney hospital - I think it is Royal Prince Alfred - people with hepatitis C are asked to wear a yellow wrist-band. The message this sends to other people is 'keep away, I am infected and dangerous'. A message that is further from the truth would be hard to find.

At this stage I wouldn't want to be treated at this hospital.

What can you do to help stop this insulting policy?

**Mrs D. Griffith
Lewisham**

[See editorial on page 2, and Council response on page 17 - Ed.]

CARBON COPIES

**Letters to Editors, found in
Sydney's daily papers which relate
to hepatitis C.**

Hep C Overkill

(Daily Telegraph)

Your article in yesterday's paper on the banned hepatitis C-infected surgeon referred to the "killer hepatitis C virus". It ended with the sentence "they have to educate people".

What a golden opportunity missed. By using the words "killer virus" you have misinformed 1.3 million readers.

Only 5-10 percent of people exposed to the virus will face a life-threatening situation, through progressing to end-stage liver failure following cirrhosis of the liver, or through liver cancer.

Therefore, 90-95 percent of people affected by the virus will not face a life-threatening situation.

Many of these people will have long-term symptoms of this condition - extreme tiredness, nausea, pain - but will not die from it.

To call hepatitis C a killer virus is misleading. Ask the 150,000 Australians living with hepatitis C and trying to cope with the social consequences. I'm sure they would agree.

**Stuart Loveday
Executive Officer
Hepatitis C Council of NSW**

Sydney Morning Herald Editorial - 31 May 1995

Objections have been raised to a practice at Sydney's Royal Prince Alfred Hospital, which the *Herald* has revealed. It is the tagging with a colour-coded wristband of patients with blood-borne viruses such as Hepatitis C or HIV. One objection which is not valid is the claim that it has overtones of Nazi-era Germany, where arm bands and other stigma were used for horrifying purposes. It is silly to suggest that a practice which has been adopted as an infection control procedure, for the purposes of saving lives, can be equated with one which has overtones of genocide. Such an emotional response has no place in debating whether the practice is an appropriate one or not.

A more reasonable objection, and one put forward by the chairman of the Australian National Council on AIDS, Dr Don Grimes, is that it could be self-defeating as an infection control procedure. Dr Grimes said such a policy had been rejected during a recent review of guidelines to eliminate the possibility of patient-to-patient transmission of HIV because of "the chance that having an armband system .. would breed a false sense of security". He makes the valid point that in a hospital, "every patient should be treated as if they are potentially infectious". This is particularly important because of the window period during which infectious antibodies are not detected.

Those who defend RPAH's policy do not dispute Dr Grimes' warning that every patient should be treated as potentially infectious. But they argue that colour-coded tags provide an additional level of protection for healthcare workers and for other patients. Far from inducing complacency, such a system should reinforce in healthcare workers the need to take additional precautions when treating patients carrying blood-borne viruses. This is particularly so for protection against needle-stick injuries.

Dr Richard West, the chairman of the NSW Branch of the Royal Australasian College of Surgeons advisory committee on HIV/AIDS, has pointed

(Continued on page 15)

NSW sets standard for infection control

Abridged from **Alicia Larriera's** article in the Sydney Morning Herald, 21 April 1995.

NSW doctors and nurses will be forced by law to stick to strict infection control rules - or face deregistration - under new regulations announced by the State Government.

The new infection control regulations released by the Minister for Health, Dr Andrew Refshauge, detail rules ranging from washing of hands, to compulsory use of sterile needles, and how to sterilise equipment.

Dr Refshauge, pledging that there would be adequate funding to ensure hospitals could afford to follow the new rules, said they would be introduced within weeks.

Details on how the infection control rules will be policed were not released.

However, a spokesman for Dr Refshauge confirmed that staff who did not follow the regulations faced disciplinary action which would range from warnings to deregistration.

Unlike the previous Government which tried and failed to legislate guidelines covering healthcare workers infected with HIV or hepatitis B, Dr Refshauge has ruled out any laws to cover testing of these workers.

There was widespread opposition from the medical profession and various professional and community groups, to healthcare workers being compulsorily tested.

The NSW Government's new regulations are at odds with a strong push by infection control experts to set up a national body that would coordinate and monitor infection control guidelines.

Professor Yvonne Cossart - Head of the Infectious Diseases Department at Sydney University - said that at present healthcare workers did not know what regulations to follow. She said that current guidelines in circulation include those of the National Health & Medical Research Council, the Australian National Council on AIDS, Standards Australia, individual State health departments and medical colleges.

Healthcare workers, hospital administrators and health policy makers are under pressure to overhaul infection control guidelines after four people who

were treated by a Sydney surgeon in 1993 contracted HIV. This happened apparently because of a breakdown in infection control procedures.

Similarly, four patients contracted the hepatitis C virus last year, following treatment at a Campbelltown private hospital.

A survey published in The Medical Journal of Australia last August found that only 44% of staff at a NSW public hospital followed infection control guidelines which require all needlestick injuries to be reported.

Under present guidelines, staff who suffer a needlestick injury should report the incident, undergo testing for HIV and hepatitis B, have counselling and step aside from any duties which could expose patients to viruses until further tests show the worker is not infected.

The guidelines do not specifically cover hepatitis C because not enough is yet known about this relatively new virus. Guidelines are needed because a NSW surgeon who has the virus has had to stop performing invasive surgery, and two healthcare workers

have become infected through needlestick injuries.

The medical journal study notes that "most injuries were due to dangerous work practices involving [needles and scalpels] and could have been avoided".

"the study of 300 staff found that 53% had suffered between one and five needlestick injuries in the previous five years"

The study of 300 staff found that 53% estimated they had suffered between one and five needlestick injuries in the previous five years.

A study by Rita Lin (NHMRC Scholar) found that of 110 needlestick injuries, HCV transmission occurred in only 3.7% of cases.

Stop infection by 'using education'

(Abridged from Jim O'Rourke's article in the Daily Telegraph Mirror on 21 April)

More government money needs to be spent to ensure infection control procedures in public hospitals are more rigidly followed, a senior surgeon said recently.

The chairman of the Royal Australasian College of Surgeons advisory committee on HIV/AIDS, Dr Richard West, said a large educational program on infection control was needed for healthcare workers.

Dr West was commenting after a study revealed casualty staff in several Sydney hospitals ignore infection control procedures - designed to stop the spread of HIV, hepatitis B and hepatitis C - sixty percent of the time.

He said he was not surprised by the findings of the study which was carried out in 1994.

Dr West said the stress of working in busy casualty sections and wards was the main reason the procedures were not being carried out.

"This Government has to put more funds into public hospitals so that staff are able to adhere to infection control guidelines all of the time", he said.

Health Minister Dr Andrew Refshauge said he would introduce regulations into parliament next month to give legal effect to stringent infection control procedures (*see previous article*).

Doctors and nurses face deregistration if they do not report they are carrying infectious diseases.

CLINICAL UPDATE -

THE 1995, TERRIGAL HEPATITIS C SYMPOSIUM

by Paul Harvey, assisted by Mary Sinclair of Alpha Biomedical Communications.

The sound of waves lapping on the golden sands of Terrigal beach provides a wonderfully romantic atmosphere for weekend get-aways, but for me, the waves simply reminded me of my home town, a nearby seaside town - The Entrance.

The symposium allowed Australian and international hepatitis C experts to get together and discuss clinical developments. Mostly, the speakers focused on Interferon treatment and the use of new testing technology that looks for presence of the virus itself - PCR tests.

Speakers included Dr Ferruccio Bonino from Italy; Dr Chris Liddle from Westmead Hospital, Sydney; Prof Geoff Farrell of Westmead Hospital; Paul Harvey representing people affected by HCV; Dr Chris Ryan of Westmead Hospital; Prof Graham Cooksley of University of QLD; A/Prof Frank Dudley from the Alfred Hospital, Melbourne; Prof Bob Batey of the John Hunter Hospital, Newcastle; Dr Karin Gutekunst, Senior Scientist, Roche Molecular Systems, USA.

There were no dramatic developments regarding hepatitis C, but the symposium was useful in that it reinforced much of our existing knowledge of the illness. Following, is a basic outline of several presentations.

Dr Bonino stressed that a major problem today is how to improve clinical management of patients. He said that improved management involves being able to answer questions such as how to identify patients who will benefit most from Interferon treatment, and whether this treatment is beneficial in patients who have no symptoms.

Prof Bonino mentioned that the major pattern of infection in Italy involved HCV subtypes 1b and 2a. He questioned why Hep C, not being very infectious, should be so widespread in the world. Dr Bonino went on to suggest that this might be due to the high rate of chronic infection, ie. the number of people who's immune system does not clear the virus.

Dr Bonino reinforced the current belief

that Ribavirin offers no real benefit for hepatitis C. He stated this therapy on its own does not seem to stop the virus from growing, and it actually can hinder our immune system to a small degree.

He spoke of the need to find out a patient's viral load, saying this was important in defining a person's condition. For example, he feels that the presence of the virus does not necessarily mean disease. He also feels that a low viral level could also mean someone is not infectious.

Further still, Dr Bonino believes that the PCR measuring of someone's level of virus can help define when is the best time to try Interferon treatment.

At this stage, the Australian medical profession does not utilise PCR technology to any great extent. In part, this is due to problems with quality control among the laboratories that would perform the test. The most effective use or role for this type of test is yet to be determined by health authorities. It seems it may be best suited to confirmatory testing of blood test where there is an unclear result - indeterminate results.

Dr Bonino hinted that the adoption of new technology (PCR) will depend on hep C specialists, the pathologists who test our blood, the scientists who are

working with hep C and our health authorities who deal with the cost of such services.

Prof Batey spoke of the procedures the government uses for monitoring the current Interferon treatment scheme.

Prescribing Interferon under the Section 100 pharmaceutical drug scheme involves ongoing patient evaluation that is monitored by the Australian Gastroenterology Institute. The Commonwealth aims to use the information to figure out the type of patient who would benefit most from treatment. The information will also be used to work out whether 6 months or more is the best treatment strategy.

Clinics and hospitals also have to be assessed if they are to be accredited as treatment centres (see page 10).

Prof Batey said a lot more information on patients is needed before we have a complete picture of Interferon treatment.

Professor Geoffrey Farrell spoke of the complications surrounding cirrhosis and Interferon treatment.

He said patients should be treated before cirrhosis develops, adding that once fibrosis is established, it seems to inevitably progress.

(Continued on page 8)



The Holiday Inn at Terrigal, venue for the March 1995 Australian Symposium on Hepatitis C.

(Continued from page 7)

Prof Farrell confirmed that a good response to Interferon was more common with patients who did not have serious liver damage.

Prof Farrell went on to discuss the type of differences in patients that affect response to Interferon. Suggested differences include a person's age, gender or ethnic background; the viral sub-type and viral load; the length and amount of Interferon treatment; and the severity of liver disease.

He added that generally, Australia has subtypes 1a & 3. Those patients with subtype 3 seem to have less severe liver disease, while those with subtype 1 more often seem to develop cirrhosis.

Dr Chris Ryan spoke of the possible situation where people experience the consequences of a severe long-term chronic disease (we hope to interview Dr Ryan on video soon).

He believes those people with a history of depression or other psychiatric problems should not necessarily be denied Interferon treatment. With careful monitoring, potential problems can be foreseen and treatment halted where necessary.

Associate Professor Frank Dudley spoke of the latest clinical trial looking at Interferon treatment - Aushep 4.

He said this research trial would possibly look at 200 patients, and would try to determine if virus subtype and viral load are the most important differences in regard to whether patients respond well to Interferon.

Dr Karin Gutekunst gave a detailed briefing on PCR testing, saying it could be useful when

you need to find out if liver damage is being caused by some other form of hepatitis,

unclear results from other tests need to be confirmed,

a parent wants to know if a new born baby is hep C positive or not,

progression of treatment needs to be closely monitored.

The Symposium provided a very useful forum for specialists peer education and networking.

It also gave the Council an opportunity to highlight the role of such community-based groups within both patient management and the overall re-



Prof Geoff Farrell, Dr Ferruccio Bonino, Dr Brian Jones, Dr Katrina Watson and Prof Graham Cooksley discuss patient case histories and best management strategies.



DEPUTY PREMIER, MINISTER FOR HEALTH AND MINISTER FOR ABORIGINAL AFFAIRS

An open letter to the Hepatitis C community of NSW.

I would like to congratulate the Hepatitis C Council of NSW on the excellent work it does in the provision of up to date information and appropriate support for people with hepatitis C in NSW. The achievements of your organisation are impressive, and a tribute to those who have been responsible for them.

Protecting patients from any infectious disease, particularly Hepatitis C, is high on the Carr Government's agenda for the New South Wales health system.

A number of commendable policy initiatives are in place and I intend to do more on this issue.

NSW Health has recognised the need for information regarding hepatitis C through the issue of an easy to read, one page fact sheet on the disease. In addition, the Department has established a number of public health measures for blood borne diseases which include screening of persons who are at risk of infection, needle and syringe exchange programs, community and healthcare worker education and infection control guidelines based on universal infection control precautions.

The Government will maintain and promote the network of clinicians in each Area and District who act as a resource for the clinical management of individuals with hepatitis C.

I will ensure that the clinics in all areas, which provide expertise in diagnosis and treatment of blood borne viruses, will be improved.

The Federal Budget allocated \$3.8 million over the next two years to provide surveillance and education services which were set out in the National Action Plan for Hepatitis C. Whilst the allocation of some dedicated funding for hepatitis C is welcomed, it is disappointing that the care and treatment aspects of the Plan were not addressed. It is my intention to lobby the Commonwealth on this issue to ensure that adequate funds are made available for the further development of care and treatment services in NSW.

The Government is currently considering the recommendations of the NSW Hepatitis C Task Force with a view to developing an implementation plan.

I look forward to a constructive working relationship with the Hepatitis C Council of NSW and wish all members and staff well in continuing to provide the excellent services that have been put in place.

Yours sincerely

Andrew Refshauge MP - Deputy Premier and Minister for Health

H EP C
IS ME
DEFINED

BY DISEASE

HEP C

MAKES NO SENSE

STICK IN AN 'M'

SEE HEMP

NO - SMOKE IT

TO FORGET IT

YOU GOT

HEP C (for a while)

CIRCUMSISED

WHAT YOUR LIVER GOT

MAGNUM NEEDLE

BIOPSY SHOT

DIDN'T HEAL

HEP C

JUST LET YOU KNOW

PRECISELY WHERE

YOUR LIVER WAS

SINCE THEN IT'S

HEP C

CIRCLE OF PAIN

FLUTTERING ABOUT

MAKING YOU DOUBT

THIS LIFE YOU GOT

MAKE YOU THINK A LOT

HEP C

CIGARETTES

MAKES HEP C

FOR ME

DOUBLE UNHEALTHY

SO YOU TAKE

VITAMIN C

PUT BACK WHAT

SMOKE AND DOPE

TOOK OUT

FORGET ABOUT

PEPSI AND COCA-COLA

CUT CAFFEINE

KEEP SOBER

HEP C

EX CHANGE

AN 'I' FOR THE 'E'

THEN YOU'RE

'HIP' WITH A C

INJECT MEDIA

MAKE IT SCARY

ANOTHER VIRUS

TO SEE OUT THE NINETIES

AND MAKE FOLKS

FRIGHTENED

OF BLOOD AND NICE PEOPLE

LIKE ME

by J.S.

Hep C notification system

Once I have a positive hep C test, what happens to the results. Where do the results go who finds out that I have the virus?

With many possible problems surrounding discrimination and confidentiality, this question is often asked by people who have had a test, or are thinking about doing so.

Briefly, the process includes your doctor, the testing lab, your local Public Health Unit, the national Infectious Diseases Surveillance System, and ultimately, the World Health Organisation.

The system does involve safeguards to make sure your confidentiality is maintained, and beyond a certain point, information becomes anonymous.

A person may go to a casualty ward or be in hospital and have blood tests done. He or she might have tests done by their family GP or local 24 hr medical centre. Alternatively a person may be tested when they donate blood, or if they have a thorough medical check up for a job.

In any of these cases, if a hepatitis C test comes up positive, it means the person has antibodies to the hepatitis C virus (HCV).

In this case, both the laboratory that actually did the test as well as the GP

who ordered it for you, will pass on the a notification to your local Public Health Unit. The notification will include your name, address, date of birth, sex, the dates of blood collection and notification, whether the test looked for antibodies or the virus itself (PCR test), and details of the doctor who ordered the tests.

In a hospital, the details are the same except that your occupation is included as well as your country of birth and whether or not you come from an Aboriginal or Torres Strait Islander background.

This information is processed by the Public Health Unit (PHU) to make sure your results are not recorded twice. In an anonymous form, the PHU then passes the statistics on to the Infectious Diseases Surveillance System. **This information does not include details of your name, address or anything else that could possibly identify you.** Statistics are also reported in the Public Health Bulletin.

On top of all this, the information eventually ends up being passed on to the World Health Organisation. This international body looks at the global spread of infectious diseases and other health problems.

Herbal remedies warning

Abridged from the Sydney Morning Herald

The Australian Medical Association (AMA) has warned people to beware of herbal preparations which do not list their ingredients, because some preparations may contain toxic chemicals and drugs.

A laboratory analysis of a herbal mixture being used for fertility treatment showed it contained high levels of steroid hormones, the AMA's Queensland spokesman, Dr David Molloy, said recently.

The level may equal those in the oral contraceptive pill, yet the mixture was being used as a fertility drug and in early pregnancy.

"A sex hormone used in the 1960s similar to the one found in this mixture was found 15 years later to have abnormal effects on daughters, with an increased incidence of some genital tract cancers," Dr Malloy said.

He said doctors were concerned about the insufficient labelling of ingredients in herbal medicines. "Even in toothpaste, you know what is in it from the label".

"We fear that toxic chemicals and drugs like antibiotics, arsenic and lead are sometimes used in common herbal remedies".

Dr Molloy said these substances had been found to have abnormal effects and some herbs had been found to cause liver and kidney problems. People should be aware, he said, that everything that was "natural" was not necessarily safe.

Interferon - where can I get it?

Interferon is a drug treatment that has been available for hepatitis C for over three years through drug evaluation trials.

This form of treatment is the only form of drug treatment currently recognised by health authorities. Studies are currently being undertaken on Chinese herbal treatments that could also provide positive results for hepatitis C.

Late last year, the Commonwealth government approved access to Interferon through a special scheme - the Section 100 Highly Specialised Drugs Program.

Within this program, patients must meet several criteria to access the drug. Hospitals and clinics also must be evaluated before being authorised to treat with the drug.

Patient eligibility criteria:

- 1 age greater than 18 years;
- 2 disease proven by liver biopsy (except patients with blood clotting problems);
- 3 one positive antibody test result, then a second test repeated between 4-6 month later;
- 4 liver function tests with ALT readings 1.5 times normal upper limit, repeated three times over 6 month period;
- 5 absence of cirrhosis or other serious liver damage;
- 6 alcohol use of no more than seven standard drinks a week;
- 7 no history of injecting drug use in the previous 12 months, unless currently drug free and stabilised on methadone program for 6 months;
- 8 for women - no chance of pregnancy while under treatment;
- 9 absence of HIV infection;
- 10 no history of autoimmune liver disease;
- 11 no history of significant psychiatric problems;

NB: The course of treatment involves 3 million units injected three times a week, and lasts for 6 months. If there is no normalisation of ALT readings after 3 months, the treatment will cease.

Treatment Centres:

Sometimes there are reasons why authorised treatment centres can not treat with Interferon. The NHMRC views Interferon as 'a potentially hazardous drug with possible serious side effects' and a drug that must be monitored closely.

Treatment centres must have adequately trained staff, ideally having participated in the recent drug evaluation trials (AUSHEP01 or AUSHEP02).

There are minimum facilities that treatment centres should have before they treat with the drug. These include:

- 1 a nurse educator / counsellor for patients;
- 2 24 access to medical advice for patients;
- 3 an established outpatient liver clinic;
- 4 facilities to perform safe liver biopsy.

In rural and remote areas, State governments may wish to designate a hospital as a treatment centre for hepatitis C, provided that arrangements are made to ensure that first rate patient care and monitoring are maintained, and that reporting to the central database is maintained.

As at May 1995, the authorised treatment centres in NSW are:

	Centre	Area	Treating?
1	Westmead Hospital	Sydney	Yes
2	Concord Hospital	Sydney	Yes
3	Royal North Shore Hospital	Sydney	Yes
4	Royal Prince Alfred Hospital	Sydney	Yes
5	St George Hospital	Sydney	Yes
6	Prince of Wales Hospital	Sydney	Yes
7	St Vincent's Hospital	Sydney	Yes
8	Sutherland Hospital	Sydney	Yes
9	Bankstown - Lidcombe Hospital	Sydney	Yes
10	Blacktown Hospital	Sydney	Yes
11	Mt Drutt Hospital	Sydney	Yes
12	Liverpool Hospital	Sydney	No
13	John Hunter Hospital	Hunter / Mid Nth Coast	Yes
14	Illawarra Area Hospital	Illawarra / Sth Coast	Yes
15	Lismore Base Hospital	Nth Coast / Nthn Tablelands	Yes
16	Wagga Wagga Base Hospital	Sth Western NSW	Yes
17	Corrections Health Service	NSW prison population	Yes
18	Bega District Hospital	Sth Coast / Sthn Tablelands	Yes
19	Orange Base Hospital	Central / Far West	July '95

Interferon does have side effects. If you are thinking about Interferon, there is written information available. A good doctor who is up to date on hepatitis C will provide information also. Your Council has information available too (see page 16).

You should find out as much as you can about the treatment. If you are keen on Interferon, a consultation with a liver specialist will be part of the Section 100 evaluation process. Here, you should have your concerns and queries written down so you don't forget to ask about them. Make sure you find out as much as you can.

If you are eligible for Interferon treatment and you've decided you want to try it, you'll end up attending the treatment centre where you should be briefed on treatment and side effects. You will be supplied with take home supplies of the drug and will have to return for regular monitoring and further supplies. Your condition will be further monitored for 6 months following the treatment to determine how successful it was. Currently, around 25% of people who try Interferon achieve a long-term remission.

[NB. If anyone who has been on Interferon wants to be taped in a short video program, please contact Paul. This video could be very useful for those people who are deciding whether to try the treatment.]

Hep C video package - will it get up?

A real need currently exists for hepatitis C educational and teaching resources. There are just no specific resources anywhere to be seen. All we have are brochures that seldom make it into pharmacies and surgeries, and the shoe-string productions of community groups.

The National Action Plan calls for education of the general community, healthcare and welfare workers, and those people either already affected by hep C or at risk of contracting it.

The National Action Plan also recognises that there is a current glaring lack of education and prevention materials.

The Hepatitis C Council of NSW has been working closely with the Centre for Education and Information on Drugs and Alcohol (CEIDA) in addressing this situation.

We are working together to produce a video package which will be used to inform people about the virus and what it means to have hep C. The video will also assist in the prevention of further spread of the virus by highlighting transmission risk situations and promoting behaviour change aimed at reducing risks.

Our objectives are to increase the number of people who are aware of the nature of the hep C virus; who can recognise transmission risk practices and reduce such practices; who are aware of how testing works and what the implications of a positive result are; who are aware of treatment choices; and who know of the possibilities for discrimination and can act to prevent this.

The objectives also include increasing the number of healthcare and welfare workers who can offer improved diagnosis, treatment, counselling, support and referral.

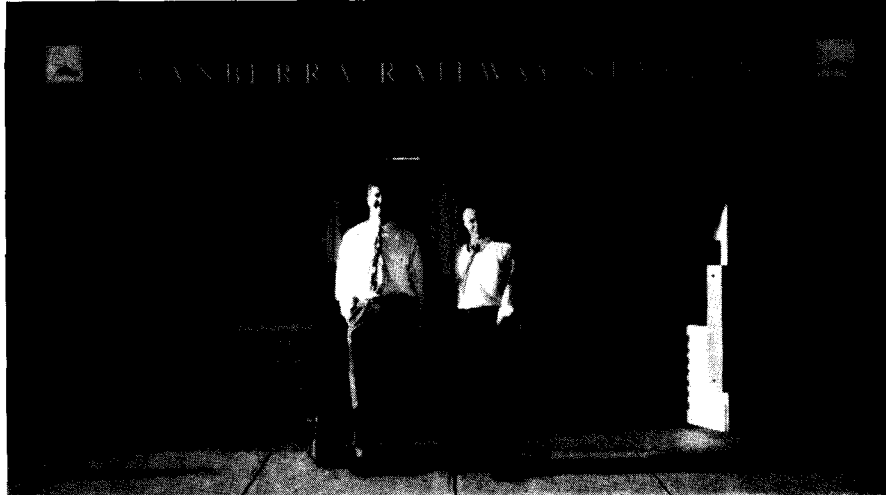
Much of the project will be contracted out to a professional video production company and will involve thorough expert consultation, script development, focus testing, casting, shooting and editing.

The finished product will be a vital tool for dealing with current ignorance and prejudice. It will only be possible though if we can get adequate funding.

The ball is in the Commonwealth's

court in this sense. Stuart Loveday, the Council's Executive Officer, is a member of the national committee responsible for education and prevention. We

have put this proposal to that committee urging the project be considered a priority.



Stuart Loveday and Paul Harvey following a meeting with Commonwealth Department of Health bureaucrats to discuss the

The news is not good at this stage. The National Action Plan:

Commonwealth is saying it has no responsibility to assist us financially.

This is totally unacceptable and we will continually draw the Commonwealth back to the policy position endorsed by the Australian Health Minister's Advisory Council and clearly outlined in the

"The support needs of people infected with hepatitis C are recognised, and the Commonwealth, States and Territories should assist appropriate community-based groups which address the needs of those people with hepatitis C."

Yellow wristbands for hep C patients continued from page 1

Dr Roger Garsia, the senior immunologist at Royal Prince Alfred Hospital and a member of its infection control committee, said the system was designed as a subtle reminder to staff and was another step in quality control.

He declined to list the infections covered by yellow wristbands, but said they included tuberculosis, which can be transmitted through droplets in the air.

In hospitals, HIV and hepatitis C are most likely to be transmitted through 'sharps' injuries - where healthcare workers accidentally sticking themselves with a needle, scalpel or other sharp instrument.

Neither HIV or hepatitis C is airborne transmitted and the three-month period between infection and the return of a positive test result means that all patients have to be treated as if infected.

The chairman of the NSW branch of the Royal Australian College of Surgeons advisory committee on HIV/AIDS, Dr Richard West, who works as a surgeon at Royal Prince Alfred, denied that the policy breached guidelines.

He said it allowed surgeons and healthcare workers to take extra precautions. Additional protective clothing could be worn, operations performed more slowly, and more experienced staff assigned to the theatre.

Dr Garsia said that in light of the State Government's decision to move to regulations covering healthcare workers and infection control procedures, it might be time to question the validity of wristbands for HIV and hepatitis C patients.

The Hepatitis C Council of NSW's response can be found on page 17.

Hepatitis C - genome sub-types explained

As research continues to examine the hepatitis C virus. We are told that several virus genome sub-types exist. Here, we try to explain just what it all means.

Every living thing is made up of chemical building blocks. These are called macromolecules. They include special fats, certain proteins and special molecules that carry the genetic code. These are called nucleic acids (e.g. DNA or RNA). Within the nucleic acids, are the blue prints for growth and development which are called genes.

Humans have gene structures. Every cell in our body carries our gene structure. This is the same for animals, as well as insects, fish, germs and viruses.

Scientists are now 'mapping' and experimenting with the gene structures of various animals and plants. Because of this work, we are now seeing the development of specialised animals and plants.

Explaining how genes relate to the hepatitis C virus can be very difficult. Perhaps the best way to do this is to use our imaginations.

Think of horses. Imagine there are six paddocks, each with twenty horses. One paddock contains large draft horses, another contains high spirited race horses, another contains quarter horses, another has palomino horses, another Shetland ponies while the remaining paddock holds Mongolian horses.

Now imagine that these different types of horses are different subtypes of the hepatitis C virus. What can we now read into the situation?

The six virus subtypes, like the horses, are all similar enough to be classed as one family - the hepatitis C virus. But the six viruses subtypes are different enough to each other to have their own character - like the draft horse is different to a race horse. Because of these different characters, the various virus subtypes can affect humans slightly differently.

What else can we read into the picture? Again, think of the horses. Within each paddock, although the twenty horses are the same breed, they are slightly different in some way. They may be of

different height or weight, or they may have manes or tails of slightly different length.

"The trouble with the hepatitis C virus is that usually, by the time the cavalry arrives, the virus has changed just enough to be unnoticeable"

Likewise, within each virus subtype there are very slight differences, or mutations. Actually, a hepatitis C virus constantly changes itself ever so slightly. Not enough to be seen as a different type of horse, so to speak, but just enough to make sure our antibodies can't find it. How much does it need to change? Using the picture of the horse, possibly only the length or colour of one of its hairs.

This is why many people are unable to clear the virus - only about 15-20% of people who catch the virus are able to naturally clear the virus. Normally, this

process of clearing viruses is the same as if we catch a flu virus and, ideally, it should work every time.

Blood cells that act like scouts find a virus and then alert the cavalry. The attack-type cavalry blood cells are then manufactured according to what the scouts saw.

The trouble with hepatitis C viruses is that usually, by the time the cavalry arrives, the virus has changed just enough to be unnoticeable.

So what control do we have over this ongoing and internal skirmish? What can we do to help ourselves?

Two things we can do are to help strengthen our immune system, and to help alleviate liver damage if it is happening (see article below).

We should consider what we put in our bodies, and how much stress we are under. A good balanced diet, possibly with vitamin supplements, and maintaining a healthy level of stress can only help. Best of all, cut down alcohol use as much as possible.

See the Hep C Review, number 10, which focuses on natural therapies.

I've got hep C but do I have a disease?

Doctor Ferruccio Bonino, a guest speaker at the recent Australian Symposium on Hepatitis C, questioned the common belief that all people infected with the hepatitis C virus have a disease.

He said, "It can no longer be said that an individual with HCV, who tests positive .. necessarily has a clinical problem or is infectious."

[There is no test currently available which can show infectiousness. Until such a test is widely available, everyone with a positive hepatitis C test result must consider themselves as potentially infectious. This is the basis of universal infection control guidelines.]

Most people automatically associate a positive hepatitis C antibody result with 'having hepatitis C'.

With hep C infection though, it is believed there is only a 20-30% chance of cirrhosis, a form of serious liver

damage. Overall, it is believed that around 60-65% of people infected will experience possible minor or significant symptoms.

The belief therefore, that infection automatically means serious disease is not true.

What does this mean for someone who has a positive hep C antibody result?

Right from the start, a patient should not assume they have some type of death sentence. This belief is not uncommon, especially when a patient is not fully counselled by their doctor when test results are given.

Find out as much as you can about the condition, and talk about how you feel.

Discuss your feelings with your family and friends if they are supportive.

Phone the Council Info & Support Line.

Talk to your doctor - with a hep C diagnosis, you should be able to expect good post-test counselling.

Hepatitis C & life insurance

a report by Paul Harvey

Hepatitis C is becoming a major issue for the insurance industry. I recently spoke to Dr John McKeand, an insurance industry representative, who outlined the current situation for people with the virus.

Dr McKeand is a member of the Risk Classification Committee and, having a medical background, is well informed on the latest hepatitis C research.

He said that in overseas countries where hepatitis B and C infection is higher, many insurance companies were facing heavy claims.

Although hepatitis C is less prevalent here in Australia, life insurance companies are keeping a close eye on how the condition affects the local industry.

Successful insuring involves skilful calculating of risks. A certain risk classification is used for assessing clients with hepatitis C. This determines the correct amount of monthly premium a company should charge in order to make an overall profit.

I asked Dr McKeand what this means for people with hep C considering taking out life assurance cover. He said that because those with the condition have a greater statistical chance of death or disability, they could expect to pay increased premiums.

He said this related to four main insurance 'products'. Income protection, life assurance, total and permanent disability cover, and trauma cover.

Income protection covers someone if they become ill or injured. The company will pay the person's normal wage for a certain period of time. Often people who are self employed take this type of cover.

Life assurance is where a person pays a certain amount of money each month - called a premium. This money is paid until the person is 65 years old, or expiration of the policy. If he or she dies prematurely, a large sum of money is paid to a selected beneficiary - usually a partner or dependants.

Total and permanent disability is cover for someone who is involved in a bad accident that leaves them dependent on family or community support.

Trauma cover pays people a sum of

money to assist in dealing with specific events such as heart attack, cancer or organ transplant.

"those with the condition ... could expect to pay increased premiums"

Dr McKeand added that people with hepatitis C would be assessed individually and would not necessarily be denied insurance cover. He highlighted the fact that a number of personal factors would affect assessment of a potential client. A future example being a

person's genome subtype.

For patients, healthcare workers, researchers, politicians or the business sector, hepatitis C is a relatively new condition and involves ongoing developments.

For example, risk classification formulae's are based on current existing data. As new data becomes available, insurance companies will review their approach.

For detailed information on life assurance issues, speak to a good consultant or telephone the Life Insurance Federation of Australia on 03 629 5751.

Hep C, what it means for me - Jane's story

After being diagnosed with hepatitis C I found little to be optimistic about. From my doctor's point of view, there seemed little I could do to help myself.

Not content with this, I went out and found a very good homeopath (as opposed to a mainly mediocre majority, the same as with any profession) and he subsequently treated me with homoeopathic medicines that helped build up my body's vitality, enabling my body to begin healing itself.

It was then only a matter of months before my condition improved. Not only was my overall health much improved, but specific ailments such as tiredness and nausea disappeared.

During this time, I followed other principles specifically for healing my liver. Every morning before eating or drinking anything, or brushing my teeth, I rinsed my mouth out with 20ml of cold pressed sunflower oil, swishing the mixture around my mouth and teeth. After 20 minutes, I spat out the now cloudy oil into a jar for disposal. I was careful not to swallow any of the oil as it contained removed toxins from my body.

Immediately I brushed my teeth and gums, rinsing well to remove any last trace of the oil.

Next, I would prepare a lemon drink using two lemons, raw honey and enough water to make up a 500 ml drink. After having the drink I would wait 20 minutes. This would be the only thing I would eat or drink before breakfast.

I also took a liver tonic bought from a large mail order herbal treatment company. This tonic was taken 2-3 times daily and although it tasted vile, it seems to have had a good effect in my case.

I also took 10 grams of vitamin C daily, divided into three doses, taken throughout the day. I used the sodium ascorbate powder form as it is non-acidic and suitable for large doses. After a few months, I cut down to 5 grams per day.

Also taken daily, in the standard dose, I used shark liver oil capsules and vitamins A and B12. I also replaced a lot of tea and coffee with dandelion tea.

So with a combination of homoeopathic treatment, and the above mentioned tonics and vitamins etc, I've managed to help my body quite well. I am so pleased that my liver function tests have now normalised. I also found meditation a great way to relieve stress and to focus on the positive nature of spiritual healing.

Jane I.

A National Picture

Around Australia, support groups and state organisations are forming. Already, we are seeing the emergence of a national federation of hepatitis C organisations. These include support groups in rural areas as well as state Councils and Foundations.

If you have family or friends in other states, here are some contact details:

Hepatitis C info/support lines.

NSW 1 800 803 990

VIC 03 280 2317

WA 1 800 800070 or 09 328 8538

ACT 1 800 803 990

QLD 07 257 3223 or 1 800 177 833

SA 08 340 0320

NT 089 41 1711 (AIDS Council)

TAS 002 24 1034 (AIDS Council)

**A CASUAL VACANCY
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COMMITTEE.
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MORE?
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332 1853.**

LIVING WITH HEP C - LISA'S STORY

I was diagnosed hep C positive in 1994 when I was pregnant with my youngest child. At that time I was not given any information or advise about how to deal with the condition, diet or anything.

When I told friends and other people that I had hep C, their reactions were worrying. I was told I had only 10 years left and I should make out my will. I was told I had something akin to HIV/AIDS. Some people believed I had a condition that would 'progress' to AIDS.

During my labour I asked if it would be safe to breastfeed my newborn. A pediatrician told me she wasn't sure if the virus would be transmitted via my breastmilk or not. I decided to play it safe and put my baby straight onto the bottle.

I was told that there was a possibility

that my baby could have hep C and should be tested at age 6 months.

When my baby was 4 months old, I was hospitalised through domestic violence. My children were looked after by my sister. She changed and

***"after 4 days,
[my sister] felt so
uncomfortable
about her family
being at risk of
catching hep C, she
decided she
couldn't look after
bub any longer"***

bathed my baby whilst wearing rubber dish washing gloves. After 4 days, she felt so uncomfortable about her family being at risk of catching hep C, she decided she couldn't look after bub any longer.

Because of attitude and ignorance in the community, for a

long time I felt very isolated and ashamed at having this 'terrible' disease.

After time though, I now feel positive and can deal with it, due in part to the understanding and wonderful people who gave me their support.

Lisa.

Donor shortage means transplant delays

Abridged from an Alicia Larriera article in the SMH

While more than 3,000 people wait for organ transplants, Australians donated only 185 organs last year - the smallest number in eight years, a new study says.

If the trend continues, about three of the 42 people waiting for a liver transplant will die before one becomes available, says a spokesman for the Australian Coordinating Committee on Organ Registries and Donation (ACCORD), Mr Phillip Dye.

There is a strong willingness to go ahead with donation if it is known that the next of kin wished it. However, the willingness declines sharply from 86 per cent to 27 per cent in cases where the deceased has not specifically requested it.

A 1985 study of attitudes found that the biggest objections were on religious grounds.

Liverpool area waits for Interferon

People from the Macarthur area with hepatitis C will hopefully be treated soon at a Liverpool clinic with Interferon, currently the only recognised drug treatment.

Centre Director, Dr John Quinn said the clinic would assess hepatitis patients for the drug treatment and provide ongoing monitoring for each patient.

The hepatitis clinic was to have been opened recently but a hitch in the funding arrangements for the carrying out of liver biopsies has led to indefinite delays.

Dr Quinn said the Bigge Park Centre, attached to Liverpool Hospital, would be staffed by gastroenterologists, infectious disease specialists and physicians.

He added that he was confident the incoming Government would make sure the additional necessary funding was made available.

Hep C News - from the Hunter region

By Leone Robertshaw and Robyn Coffey

On a cold and wintry March evening this year, a very well attended Hepatitis C Public Meeting was held at the John Hunter Hospital, Newcastle. It was wonderful to see the concerned interest from those who came - healthcare workers as well as people affected in some way.

From this meeting a branch of the State Council has been formed. The Hunter branch runs a support group which is facilitated by Steav Coady, a social worker from John Hunter Hospital. The group provides a space where people can access information and support in a safe confidential atmosphere. The evenings include a hepatitis C information segment, as well as general discussion time. For anyone interested in coming along, childcare is available if 24 hrs notice is given. We are in our third month of operation and everything is going great (see page 16 for details).

We are really excited with our new office space in the heart of Newcastle. The office will enable us to expand our information and support services.

Elections for office bearers have been called for and five people have been appointed unopposed. Congratulations to Leone Robertshaw, Keith King, Rose Anderson, Ranjit Patterjee and Robyn Coffey. This marks another important development for the local area.

We have begun developing information resources for the local area - a leaflet giving notification of the group's current activities being the first. This leaflet is being distributed to all doctors and community health centres in the region. If you can assist in the distribution of the leaflet, please give Leone, Steav or Robyn a call.

In June there will be a Hep C Information Week at the Newcastle University. Even if you are not a student come along and say hello. Please phone Leone or Steav for more details.

As you can see, with the establishment of the local group, support services in the Hunter can only improve.

On behalf of all of us in Newcastle, we extend warm thanks to Paul Harvey, Stuart Loveday, Dr John Stephenson,

Tony Butler and Professor Bob Batey for their continuing support. Thanks also to Rose for her administrative assistance.

CONTACT NUMBERS:

Newcastle:

Leone on 049 47 1206

Steav on 049 21 4763

Muswellbrook:

Robyn on 065 43 2677

On Friday 12 May, over 50 people packed a meeting room at the Muswellbrook Hospital to hear about hep C in the Upper Hunter.

Robyn Coffey, a local community welfare worker obviously spent much time organising the very successful and well attended evening, chaired by John Stephenson of the Hunter Public Health Unit.

The audience were there to hear various guest speakers talk on hepatitis C. These included - Professor Bob Batey of John Hunter Hospital, a well known local clinician and respected national

hepatitis C expert; Tony Butler, epidemiologist from NSW Health; Leone Robertshaw a local community campaigner - Paul Harvey of the Hepatitis C Council of NSW.

The guest speakers spent 45 minutes outlining the current situation for people with hepatitis C and specifically, the situation in the upper Hunter. It was pointed out that although the statistics for the area was relatively high, this reflected the high occurrence in the nearby prisons.

Following the presentations, question time stretched on for over 50 minutes. There was a great deal of interest from the audience and the speakers were kept busy fielding questions from a wide range of subjects.

These included natural therapies, prisons and hep C, interferon treatment, education and prevention, as well as how hep C relates to sport. Here, the issue was to do with contact sports such as boxing and rugby league.

Much thanks to Rob and her colleagues for proposing and organising the event. Thanks also to the guest speakers who all gave up precious weekend time away from their families.

Sydney Morning Herald editorial - continued from page 5

to several recent cases where universal precaution procedures have failed. In one case hepatitis C was transmitted in an operating theatre and in another instance it was transmitted in a patient wing, even though in both cases the staff had adopted universal precaution procedures. Possibly an additional layer of infection control procedure would not have assisted in either case. On the other hand, maybe it would have done so.

Dr West, who is a surgeon at RPA, has pointed to some practical safety steps which can be adopted in the operating theatre if a patient is identified as carrying a blood-borne virus. For example, simply by putting these patients last on the [daily] operating list could minimise the risk of patient-to-patient transmission. Other additional safety precautions suggested by Dr

West would be for senior staff to perform the surgery and for additional protective clothing to be worn. None of these could be adopted without an identification system. None of them detract from universal precaution procedures.

Organisations such as the AIDS Council of NSW and the Hepatitis C Council of NSW which have both expressed opposition to the RPA policy, are right to be vigilant about policies which unfairly and unthinkingly discriminate against those infected by HIV or hepatitis C. But such vigilance must not become paranoia. The ultimate objective must be to ensure that the spread of all blood-borne viruses is controlled. The RPA policy is a sensible one and should be maintained - [SMH].

Your Council response to this editorial can be found on page 17.

Information available to all Council members.

Please telephone, write or fax the Council if you want any of these resources. The Council's postal address is PO Box 432, Darlinghurst, NSW 2010. Our phone number is (02) 332 1853, and our fax number is (02) 332 1730.

These resources are available free of charge, or for a low cost that covers postage.

Please note - the videos can only be borrowed for two weeks at one time. You will be posted the videos and you have to pay the return postage of \$2.80.

Quote this item when ordering	Description	Cost?
Detailed Info Pack	A 22 page overview of hepatitis C which includes testing, treatment, biopsies, haemophilia, lifestyle changes, prevention, drug use, women & hep C, prognosis and a hep C glossary.	none - it is sent to all new members.
Newsletter No.8	June 1994 - includes a focus on Social Security and the Disability Support Pension.	none
Newsletter No.9	September 1994 - main feature is on Interferon treatment.	none
Newsletter No.10	March 1995 - concentrates on natural therapies.	none
Video No.1	Prof Geoff Farrell discussing Interferon treatment, plus Jennifer Holmes discussing women & hep C.	\$2.80 return postage
Video No.2	Ken D'Aran discussing homeopathy, plus Raymond Khoury discussing herbalism.	\$2.80 return postage
Video No.3	Women and Hepatitis C Forum - featuring Dr Ingrid van Beek, Ses Salmond and Cheryl Burman.	\$2.80 return postage
Report No.1	National Health & Medical Research Council, 1994 Report - <i>Hepatitis C - Epidemiology, Natural History, Control and Treatment.</i>	\$5.00
Report No.2	National Hepatitis C Action Plan - 1994	\$5.00
Report No.3	NSW Hepatitis C Taskforce Report - 1995	not yet available
Research Pack 1	includes 5 recent research papers on overview, prevention, diagnosis, serology, epidemiology.	none
Research Pack 2	includes the AGI 1994 GP's booklet, the Fairfield Hospital booklet and the Kirkton Rd research paper.	none

- RURAL SUPPORT GROUP NOTICE BOARD & CONTACT DETAILS -

CENTRAL & FAR WEST NSW

Ph Phil on 063 61 7455
or Nick on 068 82 8765
or Peter Christopher on 063 32 8505

ILLAWARRA / SOUTH COAST / SOUTHERN TABLELANDS

Ph Allan on 042 28 8211
or Bev on 044 43 7745

RIVERINA STH WEST NSW

Ph Barb on 060 23 0340
or Wagga Crisis Line on 069 21 5343

FAR NTH COAST / MID NTH COAST

Ph Robyn on 066 22 2585
or Lismore Sexual Health & AIDS Service on 066 20 2980

TAMWORTH / NTH WEST NSW

Tamworth support group
Ph Marg on 067 679134
or ph 067 68 3365
Meets 7pm, 1st Monday of the month
at the Community Health Centre, Peel Street - Tamworth.

HUNTER / CENTRAL COAST

Newcastle support group:
Ph Leone on 049 47 1206
Meets 6pm, 1st Tuesday of the month
at 'Club Med', John Hunter Hospital.
Muswellbrook support group:
Ph Robyn on 065 43 2677
1st meeting - 6pm, Wednesday 28 June
at Old St James School,
Sowerby Street - Muswellbrook.
(for more details, see next page)

Letters to the Editor

- a reply to Mr MB.

In response to your three questions:

1. For people with hep C, yes it is recommended they do have hep B vaccinations if they have not already come into contact with this virus. Hep A vaccinations are only recommended for workers at child day-care centres or people travelling to third-world countries.

2. Low iron levels are not caused by hep C infection - if the liver is stressed, the levels of blood iron may actually rise rather than decrease. Other reasons for low blood iron levels should be investigated. Cirrhosis may be a possible (though uncommon) reason for low iron levels. Ask your GP or specialist.

3. Prior to 1990, blood could not be screened. Blood banks could therefore, not be blamed for transfusion-related transmissions. Compensation does occur where negligence by a healthcare worker or hospital is the cause but this must be proved. In one proven case - in 1990, blood identified as contaminated was not destroyed and was accidentally given to 11 hospital patients.

HUNTER HERBAL TRIAL

Professor Bob Batey from John Hunter Hospital, Newcastle, has been trialling a traditional Chinese herbal treatment.

The trial involves two groups of patients both who are getting pills that look the same. One group are getting the herbs, the other group getting a pill that is harmless, but useless.

In February this year, an initial group of 32 people with hepatitis C started taking part in the controlled trial.

Prof Batey became interested in the herbs after reading Chinese research papers which appear to show the herbs have the potential to prevent liver damage.

When laboratory animals were given the herbs, they remained alive yet were given the same liver poisons that killed

their untreated buddies.

The initial results of his trial seem to show a definite sub-group of people forming.

No-one is sure who is getting the herbs, but one sub-group of patients is showing a marked improvement in

Liver Function Test results (ALTs) with no side effects.

Confirmed results will be available in August. At this time, Prof Batey will 'break the code' and find out

which patients were actually on the herb treatment.

Prof Batey is seeking more people to volunteer for the trial. If you live in the Newcastle area and wish to give it a go, phone him on 049 21 3478.

**laboratory animals
"remained alive yet
were given the same
liver poisons that
killed their buddies"**

MUSWELLBROOK & UPPER HUNTER HEPATITIS C SUPPORT GROUP INAUGURAL MEETING

We were overwhelmed by the great response to our hepatitis C information night held on 12 May.

Thanks to everyone for attending. As discussed on the night, we are starting a support group which will meet on a regular basis.

If you are seeking support, or wish to assist in some way, please come along. We have direct representation on the Hep C Council - Hunter Branch, so we should be able to tap into good resources.

**Our support group meeting is on
Wednesday 28 June**

at the

old St James School

Sowerby Street

Muswellbrook

Ph Robyn on 065 43 2677 for info.

Yellow wristbands - *your Council response*

To the Editor,
Sydney Morning Herald

Contrary to a Sydney Morning Herald editorial last Wednesday 31 May, objections to the Royal Prince Alfred Hospital policy of tagging its HIV and hepatitis C patients are based on sound infection control and public health principles.

Extensive debate among the medical profession, public health experts and community organisations has produced widespread agreement that optimum infection control is best achieved through universal infection control procedures. These assume that any patient potentially has a serious transmissible infection.

Identifying some patients as high risk leads to less rigorous infection control generally. In any case, most incidents of HIV transmission in

healthcare settings have occurred where HIV status was known.

Another serious objection is that wristbands invite discrimination by staff who may have irrational fears or prejudices. In addition to any discrimination suffered by individuals, tagging leads to a wider public health cost - it creates a disincentive for people with HIV or hep C to participate in the healthcare system.

RPAH's policy is ultimately counter-productive as well as being out of step with world best practice in infection control.

Paul Harvey

President - Hepatitis C Council NSW

Bruce Meagher

President - AIDS Council NSW

ORANGE AWARENESS GROWS

Abridged from Mark Muller's article in the Central Western Daily.

Mr Phil Mercieca and members of Orange's Hepatitis C Support Group were in Post Office Lane recently, handing out red roses and information about Hepatitis C.

An Orange resident, Phil Mercieca has campaigned tirelessly for local support services and a better deal for people with the condition. Along with other committed members of the local support group, he spent much time organising the awareness raising day.

President of the Hepatitis C Council of NSW, Paul Harvey, Federal Member of Calare, David Simmons, and local identity Glen Taylor were there to lend their support to the day.

Local hepatitis C sufferers set up the local support group late last year in the face of a stark lack of services. They aim to educate people infected, and the general public about the disease.

Since that time, some progress has been made but the majority of the community are still unaware of the details of hepatitis C. This can lead to fear and discrimination. The recent information day was just one of many efforts to redress this situation.

David Simmons is one person who has supported the local group, helping directly as well as raising the issue in Federal Parliament in an attempt to focus attention on the virus.

"This virus affects many many people and will, I believe, become a huge burden on the public health system if it continues to be ignored," he said.

"The public must be aware of the virus, and as we saw with the HIV/AIDS situation, leave behind their fears and prejudices to work towards a solution."

Mr Simmons said the only hospitals treating the condition were grouped around Sydney and Newcastle.

"But this is not an issue restricted to those areas and people in country areas must have access to similar facilities and support," he said.

David Simmons' call has been answered, Orange Base Hospital is soon to begin treating with and prescribing Interferon, the only recognised drug treatment! Good news for the people of Orange and the Central West.



Mark Muller chats with David Simmons and Phil Mercieca at the awareness day. If you have questions about local support, phone Phil or Kathy on 063 61 7455.

Hospital staff mostly ignore infection safety rules

A study has shown that casualty department staff in Sydney hospitals ignore infection control procedures designed to stop the spread of HIV, hepatitis B and C, 60% of the time, a leading surgeon said.

The story which began with this headline and leader, recently featured in a major Sydney daily paper. Does the story tell the truth? You be the judge.

The article says that casualty staff in Sydney hospitals ignore infection control procedures 60 per cent of the time.

It then quotes a respected expert who declares hepatitis C has been "put into the too hard basket" by policy makers and the medical profession.

Commenting on the actual study used as a basis for the story, the expert said he was not surprised by the findings.

"Its okay in the operating theatres, but in the wards universal control procedures are not always followed. All sorts of excuses are given to explain why they are not followed all the time."

Urgency and alarm is added to the story with the news that key infection control experts are mobilising to demand that the Federal and State governments set up a national body to monitor infection control procedures.

The actual basis of this whole story was a survey of healthcare workers in regard to the reporting of needlestick injuries, and the finding was that "that healthcare workers didn't report needlestick injury in 60% of cases."

The offending article has greatly exaggerated the significance of the report. It would have us believe that in 60% of the time, general infection control guidelines are not adhered to.

This would have us further believe that maybe bed sheets are not being changed regularly, or that needles are being reused, or that nurses and surgeons are not washing their hands or using rubber gloves.

What is seen in the media shouldn't be taken as the gospel truth, especially by those of us who have medical conditions.

- Ed.

MEMBERSHIP FORM

We welcome involvement from the membership and occasionally seek assistance with specific projects. In this regard, please complete as much of this form as possible. Our policy is to respect your privacy. All

details on this form are treated in the strictest confidence and all communication is carried out discreetly. Please complete and return with payment to the: **Hepatitis C Council of NSW**
PO Box 432
Darlinghurst NSW 2010

1. To ensure your details are correctly recorded, please complete one of the following sections.

a) For people affected by hep C, or any other interested people.

Name			
Street address			
Suburb / Town			
State		Postcode	
Hm phone		Wk phone	

b) For individual healthcare or welfare professionals.

Name			
Position			
Postal address			
Wk phone		Wk fax	
Mobile phone		Email	

c) For agencies, companies and corporations.

Organisational name			
Contact person			
Position			
Postal address			
Wk phone		Wk fax	
Mobile phone		Email	

2. Can you help with any of the activities listed below? If so, please tick any of the following boxes.

Admin and office work?	
Helping with large mailouts?	
Writing newsletter articles?	
Video production?	
Phone support work?	
Local branch work?	
Public speaking?	
Facilitating support group meetings?	
Management Committee work?	
Other?	

3. Is this application a renewal, or are you a new member? Please tick one box.

Renewal		New member	
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4. Listed below are our membership fees. Please circle one fee box.

Membership fees are due annually on 1 March. We would welcome a full year's payment, however we would not want financial hardship to prevent you from becoming a Council member and receiving *The Hep C Review*. If this is the case, please phone the office.

INDIVIDUAL		ORGANISATIONAL	
Waged	\$10	Community-based	\$50
Concession	\$25	Public sector	\$70
Professional	\$40	Commercial sector	\$70

5. Separate donations are gratefully accepted by the Council. These are tax deductible. If you make a separate donation, please record the amount and whether you want your support mentioned in our newsletter.

\$		for publication yes / no
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6. Payment. Cheques or money orders should be made payable to the Hepatitis C Council of NSW. or please debit my Mastercard / Visa card / Bankcard (circle your card type) for the amount of \$ _____

Card number										Expiry date			
										month		year	19
Cardholder's full name										Cardholder's signature			
_____										_____			

7. Declaration. I accept the the objects and rules of the Hepatitis C Council of NSW and apply for membership of the Council.

Signed _____	Dated _____
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Please do not fill in this shaded section. For office use only	Date received	Amount received	Receipt no.	Date entered	Membership no.	Info pack

THE HEPATITIS C COUNCIL OF NSW

- a brief history and background

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 was 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.

In June 1995, the Council opened its first rural branch office. The Newcastle branch serves the Hunter and Central Coast regions.

A Background

The Hepatitis C Council of NSW is an independent, community-based organisation offering assistance to people affected by the hepatitis C virus (HCV). We are primarily funded by the NSW Health Department. The range of people we deal with is wide. It includes those people infected by HCV; their partners, family & friends; healthcare & welfare workers; peer agencies & peak organisations; government departments; and also includes private sector employers.

We aim to provide assistance in the following ways:

We operate a telephone counselling and information service that gives people the opportunity to discuss their concerns in a confidential, 'safe' environment. Our trained workers in one way or another have personal experience of HCV.

We publish a detailed HCV information pack that is sent to all members upon joining the Council. It is reviewed and updated annually.

We publish a quarterly newsletter, the Hep C Review, that provides up-to-date information on clinical developments, political issues, support services, membership information and other HCV-related news.

We produce video tapes of key guest speakers. So far, such videos have dealt with Interferon treatment, natural therapies, HCV & pregnancy, legal issues and liver transplants.

We coordinate and support the development of a state-wide support group network. This form of direct support involves local people addressing local issues.

We liaise with key bodies, ensuring that the needs of people affected by HCV are taken into consideration. This area mainly involves the development and review of government or workplace policies and procedures.

To join the Hepatitis C Council of NSW, simply complete the other side of this page and return it to the Council.

The organisation provides good opportunity for volunteer work. We offer a wide range of specific projects. All involve professional training, support and supervision. Whether for job experience or personal development; whether for one day a week or one day a month; if you are interested, please telephone the Executive Officer, Stuart Loveday.