HEP REVIEW MARCH - JUNE 2015

MARCH - JUNE 2 edition 87

WINDOWS OF OPPORTUNITY 4 new treatments up for funding

A YEAR OF BETTER LIVING Your step-by-step guide to better health

"SOMETHING TO TELL YOU" Hep C & relationships

LOVE YOUR LIVER



Zh's story - living with hep B Horrorscopes • Recipes • Crossword



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Hepatitis NSW would like to acknowledge and show respect for the Gadigal people of Eora nation as the traditional custodians of the land on which *Hep Review* is published.

We'd also like to extend that acknowledgement and respect to all Aboriginal nations in NSW and across Australia.



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Our cover features Shaline and Lance from regional NSW. They volunteered to be part of Hepatitis NSW's Photocall Project. Thanks guys!

INBOX

Dear *Hep Review*, before I read this information I felt like there was something wrong with me. I denied having hep C as I felt like I was a walking disease. I felt ashamed, had low self esteem from it and just did not want to acknowledge that I had hep C. But now after reading about hep C it has changed my outlook on it and has made me change my perspective and I look forward to doing the treatment program. Thank you. C.B

Thanks so much for your letter, C. B. Don't forget you can call the Hepatitis Infoline (#3 on common calls list or 1800 803 990) if you want to talk to someone while you're on treatment. - Ed.

To the good people at *Hep Review*, I am an inmate, I've recently been diagnosed with hep C and I am on methadone. Being diagnosed with hep C is one of the most shameful feelings I have ever felt but it has made me reevaluate my life. I am drug free and I'm trying to get off the methadone program. I can't do this alone. My family, or the little family I have left, don't know I'm on the 'done so I don't think I could ever say about the hep C. I don't know where to turn and I find it so hard to ask for help, and I dare say I'm not alone.

I hope I can find some support, but I'll understand if I don't hear back. I appreciate the time you've taken to read my letter. I read your magazine whenever I get a copy. T.B

Dear T. B, thank you for getting in touch. Dealing with hep C can be hard anywhere, but jail must make it much harder. But you're right, you're not alone. We have sent you some information, and you can speak to the Hepatitis Infoline (#3 on common calls list) for information and support in regards to methadone. - Ed.

Write to us at: *Hep Review*, Hepatitis NSW PO Box 432, Surry Hills 2010 or email hepreview@hep.org.au

22 years of stories. Share yours with us.

Hep Review magazine is a lifeline for many people, linking them to news, information, views and stories. We want to hear from you about your story together we'll share it with our community. We pay \$50 for stories published. hepreview@hep.org.au



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EDITORIAL BRUCE CHERRY

t's been another blockbuster few months since the last edition. 2015 is shaping up to be a defining year in terms of access to new treatments. The Equal Treatment Access campaign update on page 6 has our latest news on that.

More broadly, the year has brought with it questions besides whether or not people have the right to subsidised access to better, more effective treatment options. Across the world, people are also asking themselves what role large corporations should have in determining an individual's health-care options.

In India, the government is taking matters into their own hands by deciding that the rights of individuals (and whole populations for that matter) come before the rights of corporations to ever-increasing

In India, the *qovernment* is taking matters into their own hands by deciding that the rights of individuals (and whole populations for that matter) come before the rights of corporations to ever-increasing profits.

profits. The Indian government has effectively implemented a fairer pricing system by refusing to limit the production of new treatment drugs to patent-holding pharmaceutical companies, and insisting that affordable generics must be available.

What this will mean for the research and development of improved treatments is another question again. How much profit is enough to justify the money spent on inventing, trialing and producing better treatment drugs?

Here in Australia this question is also being raised by the Trans-Pacific Partnership, which is close to being locked in by the federal government. The TPP gives global pharmaceutical companies far-reaching power to extend their patents in order to prevent or delay the manufacture of cheaper

generic medicines and curb subsidy programs that keep drugs more affordable in Australia and elsewhere.

One of the answers to these questions lies in reminding ourselves that just as we're all in this together as a community in NSW, we're likewise part of a global community.

Take care of one another.

Bruce Cherry

Editor

I know, up on top you are seeing great sights, but down here at the bottom, we, too, should have rights.

Dr Seuss



GET BLOODY SERIOUS

A workshop (mostly) about hep C

A comprehensive workshop that will help you work better with your clients around hep C.

The motto of this workshop is:

THINK. PLAN. ACT

This workshop can be delivered at your workplace or a regional centre with a minimum of 6 participants. It can be delivered as a full or half day.

It is also held 4 times per year at Hepatitis NSW Offices in Sydney with a maximum of 20 participants.

Check out our training calendar at www.hep.org.au for upcoming sessions or call 9332 1853 to register or arrange a workshop.

EQUAL TREATMENT ACCESS

Windows of opportunity

n March 2015 the Pharmaceutical Benefits Advisory Commission (PBAC) is considering recommending funding four new drugs (and drug combinations) for the treatment of hep C under the Pharmaceutical Benefits Scheme (PBS). These drugs are:

1. Asunaprevir (for genotype 1b only)

2. Daclatasvir

3. Sofosbuvir + Ledipasvir (for genotype 1 only)

4. Sofosbuvir

Cme Community Advocates, people living with and affected by hep C (including both the community and the workforce that supports us) made submissions to PBAC explaining why these drugs need to be approved.













OPI What treatment (if any) are you using now?

"I'm not on treatment now, because I want a treatment option that doesn't mean having to endure harsh side-effects which made it very traumatic, such as severe depression and ongoing anaemia".

PHILLIPA What do you see as the benefits of this new medicine for you?

"The new treatments are my first chance of cure in over 10 years. They would give me the opportunity for an active life and the ability to pursue my dreams".

GLENN **Do you have any comments on the consumer input process?**

"I appreciate the opportunity to make a submission and hope they approve these drugs as quickly as possible. I don't want to wait any longer for new treatments, especially when they are already available to people overseas".

LEN

How will your life and that of your family and carers be improved by this new medicine?

"I enjoy spending time with my grandchildren and don't want that time cut short by liver failure. I believe good health is a human right. All I'm asking for is my human right to good health".

JANE

What other benefits can you see from having this medicine on the PBS?

"More and more people will be able to be treated and the number living with hep C will decrease, meaning fewer transmissions. Not to mention the billions of tax-payer dollars that will be saved by people no longer presenting at hospitals with end-stage liver disease, cancer, or requiring liver transplants. All caused specifically by hep C left untreated." At last count: **4,533** people had signed the EQUAL TREATMENT ACCESS

petition.

We didn't have room to print all of the comments people left after signing, so here is a selection of comments from the people who supported EQUAL TREATMENT ACCESS to new hep C treatments.

I signed because . . .

Restricting treatment from sick people because they can't afford it, is cruel and doesn't make sense even as a cost-saving measure. Please show some common humanity and allow people access to a treatment that can save lives and potentially restore wellbeing.

Joan, Leichardt, AUS

I went through triple therapy for a year due to my genotype and it was brutal. I know through my work with the homeless more people would seek and stay on treatment if it were less so.

Harry, AUS

I am of Aboriginal descent and hep C is a big problem in our small isolated communities and some of the people don't even know that they have it and this is bringing down their life expectancy. It is very hard for people to finish hep C treatment therefore not meeting the expectations.

Catherine, AUS

I volunteered with Hepatitis NSW earlier this year and became aware of the plight of people with hep C. If there is a proven drug available in the US, Canada and Europe it doesn't make sense to withhold it from Australians.

Elizabeth, Cremorne, AUS

Unnecessary deaths can be avoided and healthcare costs reduced overall by eradicating Hep C as soon as possible. There is no time to waste!

Patricia, AUS

Making this treatment available to all is crucial if we want a world free of viral hepatitis.

Cristina, AUS

I have a family member who would benefit. She's "not sick enough" to qualify, yet would most likely be cured and thus not cost the nation for ongoing treatment.

Robyn, Byron Bay, AUS

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EQUAL TREATMENT ACCESS

WATCH the video



SIGN the petition



SHARE it with your friends



Because access to treatment is everybody's right

Correction and apology

In Edition 86 of *Hep Review* within the article 'Equal Treatment Access: Playing the waiting game', quotes on page 8 were mistakenly attributed to Phillipa and Opi.

The quotes published in the printed version of the magazine were not Phillipa's or Opi's and Hepatitis NSW and *Hep Review* apologise for this error, which misrepresented Phillipa and Opi and their views. This error was corrected on the online version of *Hep Review* Edition 86.

Hepatitis NSW and *Hep Review* are committed to a transparent and respectful relationship with the individuals and communities who we work with and for in working towards a world free of viral hepatitis.





NSW ELECTION 2015

WHAT DO WE WANT?

The NSW State Election will be held on Saturday 28 March 2015. This is a once-every-four-years opportunity to influence State policy, including on those issues which are important to you.

In the lead-up to the election, Hepatitis NSW has sought commitments from the LNP, Labor and the Greens on three key issues for our communities:

1 IMPROVE HEP C CARE

2 FUNDING THE NSW HEP B STRATEGY

3 INTRODUCE NEEDLE & SYRINGE PROGRAMS (NSPS) IN NSW PRISONS

IMPROVE HEP C CARE

We all hope that 2015 will be the year in which new hep C treatments will be approved by the Pharmaceutical Benefits Advisory Committee (PBAC), and listed on the Pharmaceutical Benefits Scheme (PBS), finally bring the treatment revolution to Australia.

However, the benefits of this revolution will be limited if new treatments are not accompanied by expanded models of care, allowing people to access treatment in as many places as possible, including through OST and alcohol and other drug services, prisons, and increased nurse-led options.

As a result, Hepatitis NSW has called on the LNP, Labor and the Greens to commit to supporting the development of, funding for and implementation of new models of care to support increases in hep C treatment numbers, without which in Australia we will see a 230% increase in the number of liver-related deaths due to hep C by 2030.

Hepatitis NSW. Working towards a world free from viral hepatitis.

Reading this before 28 March?

You can raise these issues with the candidates in your local electorate and see what they say. And if you're reading this after the election, you can of course follow up with your local member and call on them to support issues which are important to you.

No matter who wins the 2015 State Election, Hepatitis NSW will continue to advocate on behalf of people affected by hep B and C in NSW, and call for expanded hep C models of care, funding to implement the NSW Hepatitis B Strategy, and prison NSPs in coming years.

2FUNDING THE NSW HEP B STRATEGY

The first ever NSW Hepatitis B Strategy (released in September 2014) was a significant step forward in addressing an epidemic which directly affects at least 77,000 people in NSW.

However, we also believe that additional funding is required to help meet the goals of the Strategy, including increasing the number of people receiving antiviral treatment for hep B by 300%. Specifically, we have called on the major parties to support:

- Funding for programs to raise awareness of hep B, including programs prioritising people from culturally and linguistically diverse backgrounds (especially people born overseas) and Aboriginal and Torres Strait Islander people
- Funding for additional programs which increase access to hep B treatment, including by GPs and in nurse-led models of care, and
- Funding for hep B non-government organisations to more effectively represent the needs of different priority populations to government.

BINTRODUCE NSPS IN NSW PRISONS

The needle & syringe program (NSP), introduced in NSW and across Australia in the 1980s, has been successful in preventing a large number of hep C, and other BBV, transmissions. Indeed, the Return on Investment 2 study found that, between 2000 and 2009, NSPs prevented 96,667 new hep C infections and 32,000 new HIV infections.

However, the NSP is only effective when the people who need it most are able to access it. One key group who are at high risk of hep C transmission are prisoners, with 39% of NSW prison entrants in 2010 having a history of injecting drug use, and 24% of all prison entrants (and 67% of prison entrants with a history of injecting drug use) having been exposed to hep C.

It makes no sense to deny prisoners access to the most effective means of hep C prevention – sterile injecting equipment – as part of a comprehensive harm minimisation approach. As such, we have called on major political parties to support the introduction of NSPs in NSW prisons as a matter of priority to help reduce hep C and other BBV transmission.

We will aim to let you know via our website and the *Champion* newsletter what the positions are of the parties on these key issues affecting people living with viral hepatitis in NSW.

My story Wayne

My journey began at age 15 when, after getting I was 38 years old. home from work, I would venture up to the local hotel for a couple of beers and a game of pool. Here I was introduced to an older group of people who accepted me. Before long I was smoking pot and by the age of 17 I was also taking trips and occasionaly I would inject heroin.

I met Karen when I was 18 and we partied hard for the next four years. After that we decided to give up the drugs (except pot) and move from the western suburbs of Sydney to the Sutherland Shire. We lived and worked there for the next eight years before buying our first home on the Central Coast.

Karen had already retired with arthritis and I was lucky enough to get work at a local warehouse. At the age of 32 I became ill and went to the doctor who sent me for tests - all of which came back as good results. Over the next two years I was often sick until finally the doctor asked me if I had ever injected drugs. I told him yes, about 12 years ago.

It was a shock when my blood test came back hep C positive. My life was about to change big-time.

My doctor sent me to see a specialist who gave me a liver biopsy. The biopsy showed that I had cirrhosis. The specialist told me that all I could do was give up the grog and start looking after myself - he said I could live for another 20 years. So I stopped drinking and worked hard for the next four years to pay off our house. I was working two jobs, seven days a week. Before long I became too ill to keep going, so I applied for sickness benefits and eventually I got onto the disability support pension.

Karen and I decided to sell up and move up to the mid North Coast. I played golf and fished a couple of days a week. I also started drinking again, not realising the damage it would do over the next five years. I was 42 when my doctor told me that if I didn't stop drinking I would last another 12 months.

I knew what that would do to Karen so I stopped drinking and started looking after myself, but the damage was done. My stomach was starting to fill with fluid and after having CT scans I was advised to contact RPA Hospital in Camperdown, Sydney for an appointment with a liver specialist.

It was after a long drive from home that I arrived at the RPA liver clinic and met the most wonderful doctor. This was the person who guided me through the next 12 years of my life.

Those 12 years involved endless nights of cramps, days in hospital having fluids drained from my body (one time they drained 11 litres), CAT scan after CAT scan, tubes up one end and down the other. And of course, the blood tests. After 9 years I was finally on the transplant list and midway through 2011 I got the call - 'you're next'. I packed myself off to hospital to prepare for the most significant operation of my life.

On the one hand I was elated — I was getting a second chance. On the other I was saddened, knowing that someone's loved one had passed away, and that even in their grief they were kind enough to donate their loved-one's organs to save not only my life, but probably many others too.

So my transplant went ahead. It took about ten hours in the theatre and all went well. I had started recovering from the operation when suddenly my bile duct started to become blocked. I had stents inserted that increased the size of the duct. Crisis averted, the stents were eventually removed and my recovery began again.

But I still had one problem - hep C. I had a liver that was functioning well, but a virus that was already attacking it. I asked my specialist at RPA about treatment and so began one of the hardest 11-month periods of my life. I started a 48 week course of injections once a week of pegylated interferon and six tablets a day of ribavirin. 48 weeks of aches, pains, itches, depression, tiredness, mood swings - which I blamed on my feminine side - ha! I don't know how Karen and myself survived but after 48 weeks of treatment and waiting six months for my final blood test I finally got the news I'd been waiting, hoping and praying for.

The hep C virus was no longer within my body and my new liver was working normally for the first time in more than 20 years. Finally Karen and myself could get on with some sort of a normal life.

To all the people that helped me on my journey, all the nurses, the staff at RPA Hospital, the doctors - and especially one professor, thank you for your kindness and all the professionalism shown to me over the last 11 years. And to all those people out there suffering from illness, stay strong, keep remembering there is light at the end of the tunnel and be positive because new treatments for hep C are coming and from what I hear there are few side-effects and only twelve weeks of treatment. I wish I could have had that treatment! But it doesn't matter now because I beat the "devil bastard" thing - yippee!

I would also like to thank *Hep Review* and all the Hepatitis NSW staff for the assistance on the *Hepatitis Infoline* and the stories and educational material published in the *Hep Review*. It was of great use and a good read so once again thanks to everyone for their help and I'm sure I'll enjoy the rest of my life.

Hep Review thanks Wayne (not pictured) for sharing his story.

We want to hear from you about your story - together we'll share it with our community.

hepreview@hep.org.au

LOCALNEWS News - New South Wales - Australia

HEP C SENATE INQUIRY

The House of Representatives Standing Committee on Health has been conducting an inquiry into hep C in Australia since the start of December 2014. Looking not only at the all-important new treatments, but a wide range of relevant issues, the inquiry has been described as a catalyst that can help turn the tide on the rising death toll from hep C-related liver disease. "It shows real leadership to tackle the problem head on," said CEO of Hepatitis Australia Helen Tyrrell.

In light of the recent release of the Australian Government's Fourth National Hepatitis C Strategy, this inquiry shines a national spotlight on hep C that is long overdue and hugely welcome. It also highlights the considerable challenge for the Federal Department of Health and its partners to meet the treatment and prevention targets in the strategy, unless new treatments are approved and efforts to reduce transmission are ramped up.

Hepatitis NSW encouraged *C me* Community Advocates, community members living with or affected by hepatitis C and organisations across the sector to make written submissions before the deadline of 27th February 2015. Hepatitis NSW also made a detailed submission to the Committee. Copies of submissions to the inquiry should be published on the Committee's website.

You can also read the full transcript of the evidence from the Sydney and Melbourne hearings at www.aph.gov.au

Edited highlights are available on the Hepatitis NSW website:www. hep.org.au/campaigns where the potentially "game changing" outcomes of this inquiry will be reported in full.

ABORIGINAL HEP C RATES 3 TIMES HIGHER THAN REST OF POPULATION - INQUIRY HEARS

As rates of hep C decrease among Australians overall, it is three times higher and rising amongst Aboriginal people in Australia.

Mainstream medical services are failing Aboriginal communities, where the rate of Hepatitis C is rising, the National Aboriginal Community Controlled Health Organisation (NACCHO) told the federal Senate inquiry into hep C.

The inquiry by the standing committee on health is examining the prevalence of the disease, testing and treatment options, associated costs, and methods to improve prevention and reduce stigma associated with it.

The differences between overall hep C rates and those amongst Aboriginal people were published in a 2013 study by the Kirby Institute. The worsening problem is mainly due to higher rates of unsafe drug injecting associated in part with lack of access to sterile equipment and higher rates of incarceration in Australian prisons which despite high rates of injecting drug use and sharing of injecting equipment, do not provide access to sterile needles.

Lisa Briggs, CEO of NACCHO, said current mainstream medical services are failing Aboriginal people through a lack of access and affordability.

"For Aboriginal people to remain well and healthy, they need accessible and affordable health care and they need services that are able to manage and look after their long-term conditions," Briggs said in an interview with Guardian Australia. "There are not a lot of bulk billing providers in the country, and that covers their affordability. You don't have many bulk billing providers that also provide walkins ... and that's another benefit our health services provide."

People living with hep C are likely to also have other health issues, including mental illness, addiction and diabetes, Briggs said, which require a thorough and allencompassing medical response.

"Aboriginal Community Controlled Health Services have proven time and time again to be the best model to provide comprehensive primary health care for these complex needs," she said.

The high rate of Aboriginal incarceration cannot be separated from health problems like hep C, said Briggs.

Despite making up just 2% to 3% of the general population, Aboriginal people account for 27% of the total prison population.

"It makes a huge difference because they're in confined areas where injecting drug use is part of the system, regardless of what prisons may say," said Briggs.

The issue is further complicated by the lack of hep C prevention services attached to Aboriginal Community Controlled Health Services.

"We've also called for more of our Aboriginal health services becoming [needle syringe programs], and that means that they're able to provide clean needle syringe programs so it's more accessible to clients that are injecting drug users. That will help minimise contraction and spread," said Briggs.

LOCALNEWS News - New South Wales - Australia

The decision whether or not to provide sterile injecting equipment is a complex one for these services and despite the evidence that NSP is the most effective way of preventing the transmission of blood-borne viruses amongst people who inject drugs, very few Aboriginal Community Controlled Health Services offer their communities access to NSP.

Abridged from guardian.com

ROLE FOR PHARMACIES IN FUTURE OF HEP C TREATMENT DELIVERY

Pharmacies could coordinate care for people with hep C who are engaged with methadone programs, the Senate Committee on Health has heard.

In January at the Senate Committee in Melbourne on Health inquiry into hepatitis C in Australia, Member for Gilmore Elizabeth Sudmalis said in regional areas an effective methadone program worked through pharmacies and asked whether there was a model for hep C treatment that could be rolled out in the same way.

St Vincent's Hospital department of gastroenterology director Professor Alex Thompson said this was a "fantastic" idea, as therapy could be directly observed with methadone clinic clients, a high-risk group for hep C. "You could incorporate directly observed therapy for hepatitis C into those clinics."

Not for profit substance use policy and education organisation Penington Institute CEO John Ryan said that people using methadone programs saw their pharmacist very frequently, and there was an opportunity to use this treatment interface to improve holistic health needs. One of these key priorities could, and should, be hepatitis C treatment, he said. Pharmacists could educate and support the patient about the benefits of treatment prior to, and assist them through, the period of their treatments, he said. It would be reasonable to expect to see an increased uptake of hepatitis C treatment, were such a program rolled out, Ryan said.

The alcohol and drug section of the Department of Health was quite isolated from the communicable diseases sector, and the number of pharmacological therapy prescribing doctors who were proactive in relation to hepatitis C was very small, he told the Committee.

"But there is some infrastructure there. People are in contact with health professionals, and they often have ongoing and close relationships with their pharmacists.

"We should be contemplating the role of pharmacy as part of the allied health approach to coordinated care in relation to hepatitis C.

"It would be a terrific model of care."

Abridged from pharmacydaily.com.au

REPORT SHOWS CHALLENGES AHEAD TO MEET HEP B TARGETS

Hepatitis NSW welcomed the release of a new report which shows hepatitis B diagnosis, monitoring and treatment rates across Australia by Medicare Local.

Speaking on World Cancer Day, February 4, Hepatitis NSW CEO

Stuart Loveday said ASHM and VIDRL's Hepatitis B Mapping Report showed that there are significant challenges ahead to meet targets under the recently released National and NSW Hepatitis B Strategies. "It is clear that both the Federal and NSW Governments will need to invest strongly in this area to ensure that commitments to increase vaccination, diagnosis and treatment rates are met," Mr Loveday said.

The Report reveals that only 5% of the estimated 220,000 Australians living with chronic hepatitis B are currently receiving antiviral treatment. This compares to a treatment target of 15% in the Second National Hepatitis B Strategy 2014-2017, and the historic first ever NSW Hepatitis B Strategy 2014-2020's target of increasing the number of people receiving treatment by 300%.

"Encouragingly, NSW has the highest hepatitis B treatment rate in the country, at 7.6%, and is also home to the only three Medicare Locals where treatment is currently above 10%," Mr Loveday said.

"However, in no Medicare Local, either in NSW or across Australia, is the treatment rate for hepatitis B at the agreed minimum level, of 15%, demonstrating just how far there is to go."

Similarly, the Report shows that meeting the National Strategy target, to increase to 80% the proportion of people living with hepatitis B who are diagnosed, will be a significant challenge.

"With 43% of people living with chronic hepatitis B unaware of their status, Governments and the community sector need to work together to increase testing among priority populations." said Loveday.

WORLDNEWS NEWS - INTERNATIONAL

HEP C RATES IN INDIA

Data analysis from 14,481 people from 15 cities and 11 states in India who went to a drop-in centre for people who inject drugs that provided certain HIV prevention services has found hep C rates of 37.2%.

The participants had an average age of 30 years and had illicitly injected drugs in the previous 2 years.

Overall, 92.4% of participants who injected drugs were male, 40.7% were married and 39.2% had a primary school education or less. Nearly half of the people (47.7%) personally reported sharing drug injection paraphernalia at least once and 42.2% showed evidence of harmful alcohol abuse or dependence.

The study also showed that being male, visiting an opioid substitution therapy centre, being younger at the time of first injecting, visiting a needle syringe program, history of sharing injecting equipment and injecting a combination of drugs were all associated with the likelihood of having hep C.

Further analysis showed that hep C was more common among people who used drugs who were living with HIV, compared with participants who did not have HIV. A history of HIV testing, knowledge of being positive for HIV, higher education and higher community antiretroviral treatment coverage were associated with knowledge of being positive for HCV.

"The availability of [direct-acting antivirals] for the treatment of HCV has sparked optimism on the possibility of global eradication of HCV," Sunil Suhas Solomon, MBBS, PhD, MPH, of Johns Hopkins University School of Medicine said. "However, cost is being seen as the biggest barrier — the findings of our study show that even if [direct-acting antivirals] were freely available in India currently, there are several challenges to successful delivery of therapy that are seldom discussed."

Solomon added: "Until [directacting antivirals] do become available, programs need to focus on improving treatment literacy, HCV testing and access to harm reductions services alongside negotiations to bring down cost, so that when treatment does become available we are in a position to deliver it in an efficient manner."

Abridged from healio.com

GILEAD SEEKS REGULATORY WAIVER TO SPEED NEW HEP C DRUG ACCESS IN INDIA

Gilead Sciences announced it is extending licensing agreements with eight Indian generic manufacturers to include rights to make a yet-to-be approved drug known as GS-5816 in combination with Sovaldi (sofosbuvir).

The company says the new combination, if approved, would be the first treatment that effectively treats all six genotypes of hep C. Should this be the case, the drug would be a major breakthrough for treating hep C in the developing world where it is often difficult and expensive to conduct genotype testing.

GS-5816 is currently undergoing phase 3 clinical trials, which Gilead expects will be completed in the second half of 2015. However, in a bid to speed GS-5816 to market, Gilead will ask India to "waive clinical trials [requirements] and expedite approval for the compound," according to the news site Bloomberg.com

This kind of request has been made before. In 2014, India's Central Drugs Standard Control Organisation (CDSCO) issued an order allowing the country's "clinical trial in Indian population" to be waived for drugs that are approved in other countries "in cases of national emergency, extreme urgency, and epidemic"

However, Gilead's request comes just as its market access strategy in India has experienced major setbacks.

In September 2014, Gilead said it would license Sovaldi to multiple generic manufacturers in India. The licensing agreement would allow the generic manufacturers to market Sovaldi in India and 90 other low- and middle-income countries. Gilead has said it plans to sell Sovaldi for US\$900, and expects licensed generic versions to cost less.

On 13 January 2015, India's Patent Office rejected a patent application for a compound produced by the body as it metabolises sofosbuvir. Gilead has said the patent rejection will not change its plans to sell the drug in India, and that its "main patent applications" are still being reviewed.

Gilead's licensing plans have also come under fire by some accessto-medicines groups such as Médecins Sans Frontières (MSF). The group has been critical of Gilead's voluntary licensing agreements, arguing they "fall short of ensuring widespread access to [Gilead's] new drugs." Despite the inclusion of GS-5816, MSF says the terms of the expanded licensing agreement are limiting due to restrictions on where the drug can be sold.

Abridged from raps.org

WORLDNEWS NEWS - INTERNATIONAL

SOVALDI & HARVONI ON SPECIAL IN GERMANY

U.S. biotechnology company Gilead has conceded its first discounts in Germany on its hep C drugs Sovaldi and Harvoni, German business weekly WirtschaftsWoche reported.

The head of Gilead's German operations told the magazine that discounts from the list price of 60,000 euros (\$86000AUSD) per treatment had been negotiated with four of Germany's statutory health insurers but declined to give the size of the discounts.

"Thirty-five percent of people with statutory health insurance are already profiting from the discount agreements," Carsten Nowotsch said in an interview, adding that more such contracts could follow.

Germany is Europe's biggest market for medicines, and dozens of healthcare agencies in Europe and as far away as Japan use German prices as references for their own.

Abridged from fiercepharma.com

EU APPROVES NEW HEP C COMBO TREATMENT

Drugmaker AbbVie Inc. has had its new, all-pill hep C combo treatment approved for use in the 28 European Union member countries.

The company said the European Commission granted marketing authorisation for the combination of Viekirax and Exviera. Viekirax itself is a combination pill containing antiviral drugs ombitasvir, paritaprevir and ritonavir; Exviera is a single pill containing dasabuvir.

It's already approved in non-EU countries Switzerland, Norway, Iceland and Liechtenstein, plus Canada and the U.S. In some countries, Viekirax and Exviera are sold separately, while in others they are packaged together under the name Viekira Pak.

They're part of the new generation of highly effective, easy-totolerate, short-duration hep C treatments. Rival company Gilead Sciences Inc. has two such drugs, Sovaldi and the slightly newer combo pill called Harvoni.

In patient studies, AbbVie's Viekirax and Exviera cured 95 percent to 100 percent of patients with hep C genotype 1 – the most common in Australia, Europe and the U.S.

The EU approval is for patients with genotype 1 and, for patients who have genotype 4, combining those pills with the drug ribavirin.

Abridged from nzherald.co.nz

TRADE AGREEMENT LIKELY TO DRIVE UP COST OF MEDICINES

The Trans-Pacific Partnership (TPP) is a deal currently being discretely negotiated with countries bordering the Asia-Pacific, including Australia, the US, Canada, New Zealand, as well as several countries in Latin America and Asia.

Many organisations, including the World Health Organization, are speaking out saying that the TPP could lead to higher prices for medicines, through:

1. Stronger monopolies leading to higher medicine prices

Pharmaceutical companies already have patent rights to charge high monopoly prices for new medicines for 20 years before we can access cheaper generic medicines. However, US trade negotiators are demanding stronger monopolies in the TPP, which would further delay the availability of cheaper medicines. Australians would have to pay higher prices for medicines, and in developing countries the effect would be disastrous.

2. Undermining the Pharmaceutical Benefits Scheme (PBS)

There are also proposals in the TPP which would restrict governments' ability to make medicines affordable, such as Australia's Pharmaceutical Benefits Scheme (PBS).

In the US, where there is no national system to regulate the price of medicines, the wholesale prices of new medicines are three to ten times higher than the prices in Australia, retail prices are even higher and many people cannot afford to buy medicines.

TPP proposals to weaken the PBS would mean higher costs for government which would likely be passed on to consumers.

Trade Minister Andrew Robb has made statements that suggest the government is not prepared to compromise the PBS or other areas of health policy in the TPP negotiations. However, no absolute commitment to protecting Australian consumer rights to affordable medicines has been made.

Prime Minister Tony Abbott has added to this uncertainty, making one thing clear: that completing the trade negotiations will involve some "horse trading".

Due to the secrecy of the negotiations, it is not clear yet how the Coalition will weigh health issues against economic priorities.



Hepatitis NSW **PHOTOCALL PROJECT**

Your photos, your stories

Share your photos with your communities.

Email us at hepreview@hep.org.au for more information.





We remember

ALEXANDER WIGHTMAN

Alex was one of the people who began the community response to hep C in Queensland. Alex helped pioneer the Hep C Council of Qld and was co-Chair of the management committee in 1998.

Alex was a great supporter of peerbased drug user groups, clinical staff and of community workers and contributed to the establishment and growth of the hepatitis services and resources we have today.

Alex died on 16th January, 2015, aged 45 years.

TIMOTHY MOORE

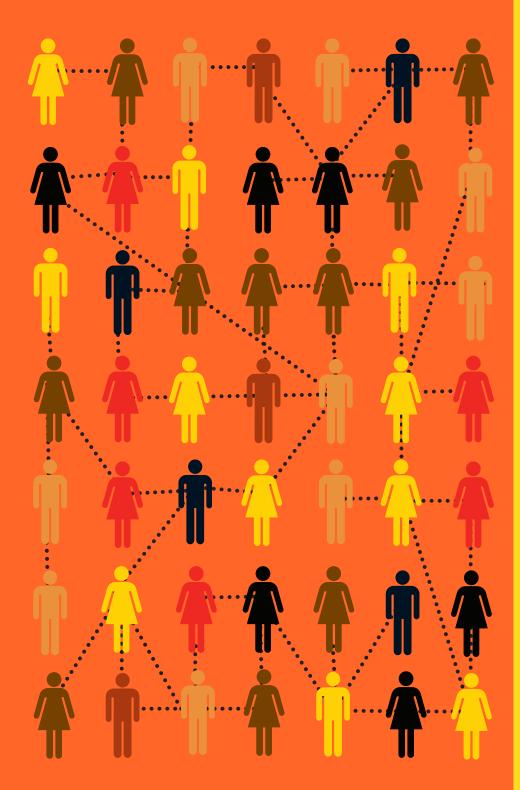
Timothy worked at NUAA in its early years, and went on to lend his intellect, wisdom, committment and quiet achievements to the Redfern Legal Centre, AFAO and VACCHO.

His friends and colleagues remember Tim as a thoughtful, generous and gentle man who shared so much and guided so many.

nages by Exposition by RAF

hepcaustralasia.org

The largest online support community for people living with hep C in Australia



hepcaustralasia.org is proudly supported by Hepatitis NSW

"What I love about hepcaustralasia is that it gives me a place to go where everyone is in the same boat.

We can talk freely about our experience without having to disclose to the wider world.

And, most importantly, it provides valuable advice and support for those of us on treatment.

It is a long, hard road but it's made a lot easier by having sympathetic, like-minded people to talk to."

Dee hepcaustralasia forum moderator Charlie Stansfield takes a look at some of the ways that hep C can impact relationships.

SOMETHING TO TELL YOU

Charlie Stansfield

rom cut ties, to deeper bonds, talking about hep C with loved ones can be a complex process and one that means that people living with hep C may be more experienced than most at navigating issues of trust and change in their personal lives.

When Naomi, 60, a community health care worker and mother-of four from Victoria received a distressed call one day from her eldest daughter she had a sinking feeling that it might be related to hep C.

"She was six months pregnant with her second child and had just been for a series of tests. We shared a GP and I think he slipped a HCV test in with the rest of her bloods and I have a feeling he did that because he obviously knew my status."

Naomi's daughter had just been diagnosed with hep C.*

"She asked me to come and pick her up, so I did. We sat in the car and she cried and said, 'I have no idea how I got this.' and I had to take a deep breath and say, 'I know. I think you got it from me."

It was the first time that Naomi had disclosed her status, and history of drug use to any of her children. Her daughter's situation prompted a host of painful and conflicting feelings.

"I had to deal with a lot of guilt as a mother, when she was a baby I'd been so anti-additives or chemicals in her diet etcetera and all that time I had unknowingly infected her with hep C."

Sixteen years later, while they get along fine, the virus has left its mark on their relationship.

"I think we both avoid the subject - neither of us wants to upset the other. She hasn't told her children (two of whom are adults). Her work doesn't know and neither do any of her friends. When she and I talk about it, which is rarely, we do it really carefully. She will ask me for health information because she knows I have connections in the field, but it is never discussed in terms of emotions or feelings, or how she contracted it."

* It's important to note here that a doctor should never 'slip in' a test for hep C. Testing for hep C should involve discussion with your doctor before and after testing. If a doctor runs a test for hep C without your informed consent, then they are in breach of medical guidelines and rules governing their practices. Ed.

To most folks reading this, it's no secret that hep C Couple and Family Therapist Matt Garrett from impacts on life – work, recreation, and relationships. Naomi's story is a particularly poignant example of that. More than fatigue or foggy mind, nausea or health complications it seems to be stigma that has the potential to damage relationships.

Stigma has a complex impact, but perhaps most common is the way it can silence us. We may not disclose for fear of rejection, or because we don't have the energy to educate our friends, or provide the backstory that is often required. We may disclose to our partners, who then help carry our struggles with hep C – on treatment or not. Occasionally we may disclose to someone we trust and they let us down, so we don't risk it again.

Donna, 55, tells of having told a close friend she had hep C, "My best friend, who I loved dearly, dropped out of my life almost immediately. I told her over dinner one night and she showed great empathy, however, from that day in three years I've only seen her three times ... (she) just dumped me with no reason and never spoke about why."

Janine, 53, talks of the difficulties that came with not disclosing to her family, "Our son, who's 33 years old, is our only child. He's married with our first grandchild...he knows I am having treatment for my liver but doesn't know the true reason. I have had to fudge my way around it."

The difficulty is that the more we hold back, the less connected we can become to the people who matter in our lives, which then reduces the chances we have to enjoy those relationships. Shell who is in her 50s, says "It puts a barrier between me and potential friends - I am wary of getting too close to people."

The way we approach disclosure and the reaction we get from friends is often an indicator of the health of the relationship. In other words, disclosure, like anything that takes a relationship beyond the surface, can expose the fault lines. While in some cases we're well advised to walk away from a person or a situation that doesn't support us, or worse, kicks us when we're down, sometimes it can scary than hep C." pay to wait and see.

Relationships Australia reminds us that relationships are actually not made of stone; they're capable of change. So, if we receive a negative response initially, it might not be the end of the story. "There are many examples where one person having a stigmatised illness has actually pulled people together, if it can be worked through successfully, it can be very powerful for both."

Matt refers to diagnosis, treatment and health complications as "sliding door moments" in the life of a relationship. They are the things nobody plans for, that take us on a path we hadn't expected, but as Matt often says to those dealing with sudden, unwanted change of all kinds, "Instead of going into denial, or closing off, can we stop and explore this new place we've landed in?" Doing so often requires work. Those of us affected by the illness might need to accept that other people's reactions are often rooted in fear and misunderstanding. Sometimes fear manifests as withdrawing – for a time – sometimes it manifests in asking a series of insensitive questions that we have to grit our teeth and endure (and then de-brief with our other friends who also know first-hand about hep C).

Matt explains, "Sometimes it helps to see another person's reaction as part of their stuff – they might be really struggling, and they might not want you to know they are really struggling." He goes on to say, "People sometimes pull away because they just don't know what to do or say. If we can recognise this, and name it, we can allow that other person to express it. That might help bring us closer."

It's also understandable when living with the fear of stigma to be acutely sensitive to people's reactions or to anticipate rejection where there may not be any.

There's something to learn about being open, creating space to be surprised by people. As someone once said to this writer after an angstridden disclosure, "Oh, is that it? Well I'm sorry to have to tell you this (melodramatic deep breath) but there are things about you that I find much more



Hepatitis NSW

offers free counselling for people living with hep C and their loved ones.

To speak to someone about Let's Talk counselling, or about any of our services, call **1800 803 990** or to find out more visit www.hep.org.au/lets-talk

Charlie Stansfield is a writer and psychotherapist in private practice in North Ryde and Chippendale. Dealing with stigma head-on could be something we do to try and achieve more authentic relationships. We might need to take a leap of faith when we disclose to family or friends. Naomi recalls that her daughter's diagnosis prompted her to share her own status with the rest of the family. Their reaction surprised her – it was loving and supportive and Naomi says she "...realised that I had shown very little faith in my children to manage the situation. I hadn't trusted them like perhaps I could have."

Lucy, 52, is a psychotherapist living with hep C. She believes that treatment can make us feel "Isolated and alone regardless of having supportive relationships, it's like a side-effect of treatment." She also reflects that part of the struggle with hep C is to have to learn to ask people for help. "For lots of us asking for help is excruciating. We have to be willing to be vulnerable. If I did treatment again, I would do this, for myself but also for my partner. Watching him stoically doing everything when I was sick, was very, very difficult, and it had an impact on our 24 year relationship."

Asking for help and standing up to stigma are intensely personal things that we all have to do in our own way and our own time. But most people value authentic relationships, ones in which we can be ourselves, hep C – and all. Matt Garrett believes that "One of the main things people can do to help both themselves and their relationships (through times of stress and illness) is to maintain hope. There is enough evidence in the research now that identifies hopefulness as the most powerful incentive to recovery."

About a millennium and a half ago, way before hep C or stigma had a voice in the language of life and relationships, St Augustine of Hippo wrote on a similar theme: "Hope has two beautiful daughters, their names are anger and courage. Anger at the way things are, courage to see that they do not remain the way they are."

There are as many creative ways to channel our anger and develop our courage as there are people with hep C. To push back and limit the impact of hep C on our relationships is up to each of us to do, in our own way, one step at a time.

I'd like to thank the people who shared their stories about relationships for this article.

hoosing to stay with relationships that get rocky after hep C might require a bit of adjustment all around. Treatment side-effects or living with the symptoms of hep C can stretch the healthiest of relationships, so it is good to try and look after them.

Here are three strategies for caring for relationships under strain.

PATIENCE

If you're dealing with a relationship that is being impacted by treatment or health issues, give it time. Remember that things change.

If you're the person affected by the illness look after yourself as much as possible and try to have friendships and connections with people who can support you no matter what – hepcaustralasia.org is a great place to start.

If you're a carer make space for yourself and ditto above.

"Patience is bitter, but its fruit is sweet." Jean-Jacques Rousseau

EDUCATION

Make sure you're informed about the illness so that if you need to explain it to loved ones you can do so in clear, simple language and be ready to answer their concerns or questions.

Remember a lot of their clumsier questions probably reflect their own anxieties about health, wellbeing, and even mortality, and aren't necessarily about you!

"Education is the most powerful weapon which you can use to change the world."

Nelson Mandela

ASK FOR HELP

Far from being a sign that things are broken and need fixing, seeking professional help through relationship or individual counselling can be a positive sign that you value yourself and your relationships.

You can seek professional relationship help about any kind of relationship, not just intimate or family ones.

Gendry: 'If you need help, bark like a dog.' Arya: 'That's stupid. If I need help I'll shout "help".' Arya Stark, Game of Thrones





"Would you like to talk to someone who understands your culture, and what it's like to be on hepatitis C treatment?"

(02) 9515 1234

www.mhahs.org.au



We understand that hepatitis C treatment can be difficult and can provide you with support in your language. Ask the nurse or social worker for information in your language about this service. The service is free and confidential.

Ye te ase se, ebere a obi woreko Hepatitis C yare no ye bere a emu ye den, na yebetumi aye wo moa wo wankasa wo kasae mu. Bisa nurseni anaa wo apomden dwumayeni no wo nsemfua fa w'ankasa wo kasae mu. Saa moa yi nso yede ma wo a, wo rentua hwee, na eye kokoa mu nsem nso.

အသည်းရောင်အသားဝါရောဂါ 'စီ' ကုသခြင်းသည် ခဲယဉ်းသော ကုသမှု ဖြစ်နိုင်သည်ကို ကျွန်ုပ်တို့ နားလည်ပါသည်။ ကျွန်ုပ်တို့က သင့်ကို သင့်ဘာသာစကားဖြင့် ကူညီပံ့ပိုးမှု ပေးနိုင်ပါသည်။ ဤဝန်ဆောင်မှုအကြောင်း သင့်ဘာသာစကားဖြင့် သိလိုလျှင် သူနာပြုသို့မဟုတ် လူမှုဝန်ထမ်းကို မေးပါ။ ဤဝန်ဆောင်မှုသည် အခမဲ့ဖြစ်ပြီး လုံခြုံသိုသိပ်မှု ရှိပါသည်။

Mi razumijemo da nije lako prolaziti kroz liječenje hepatitisa C pa vam možemo pružiti potporu na vašem jeziku. Pitajte medicinsku sestru ili socijalnog radnika za informacije o ovoj službi na vašem jeziku. Usluga je besplatna i povjerljiva.

Γνωρίζουμε ότι η θεραπεία για την Ηπατίτιδα C μπορεί να είναι δύσκολη και σας παρέχουμε στήριξη στη γλώσσα σας. Ζητήστε πληροφορίες στη γλώσσα σας σχετικά με την υπηρεσία από νοσηλευτή ή κοινωνικό λειτουργό. Η υπηρεσία παρέχεται δωρεάν και με εχεμύθεια.

Kami mengerti bahwa di dalam perawatan Hepatitis C dapat menyulitkan dan kami dapat memberikan dukungan dalam bahasa anda. Tanyalah kepada perawat atau petugas sosial untuk informasi di dalam bahasa anda untuk pelayanan ini. Pelayanan ini adalah bebas biaya dan rahasia.

យើងយល់ថាការព្យាបាលជំងឺថ្កើមប្រភេទ C អាចជួបប្រទះការពិបាកនិងអាចជួយ លោកអ្នកតាមរយ:ការគ្រាំទ្រជាភាសារបស់លោកអ្នក។ សូមសាកសួរគិលាឝដ្ឋានយិកា ឬអ្នកធ្វើការសង្គមកិច្ចដើម្បីទទួលបានពត៌មានជាភាសារបស់លោកអ្នកអំពីសេវា កម្មនេ:។សេវាកម្មនេះនឹងផ្តល់ឱ្យដោយមិនគិតប្រាក់នឹងដោយសំងាត់។

Ние разбираме дека лекувањето на хепатит ц е тешко, и ние можеме да ви пружиме поддршка на вашиот (мајчин) јазик. За информации на вашиот јазик во врска со оваа услуга, прашајте ја медицинската сестра или социјалниот работник. Услугата е бесплатна и се чува во тајност.

Nós sabemos que o tratamento para a hepatite C pode ser difícil mas nós oferecemos apoio em sua própria língua. Pergunte ao enfermeiro(a) ou ao(à) assistente social por informacões sobre os nossos serviços em sua própria língua. O atendimento é gratis e confidencial.

Tinonzwisisa kuti kurapwa kweHapatitis C kunogona kunge kwakaoma naizvozvo tinokwanisa kukupai rutsigiro nemumutauro wenyu. Bvunzai mukoti kana mushandi wezvemagariro akanaka eruzhinji (social worker) nezvezvinyorwa zviri mumutauro wenyu zviri maererano nechirongwa cherubatsiro ichi. Rubatsiro urwu rwunopiwa pasina muripo uye muchivande.

Nosotros entendemos que el tratamiento de la Hepatitis C puede ser difícil y le podemos proveer de apoyo en su idioma. Pídale a la enfermera o al trabajador social que le dé información en su idioma acerca de este servicio. El servicio es gratuito y confidencial.

เราเข้าใจว่าการรักษาโรคตับอักเสบซีเป็นเรื่องยากและเราสามารถให้ความช่วยเหลือและ สื่อสารกับคุณได้ ในภาษาของคุณ สอบถามเพื่อรับข้อมูลที่เป็นภาษาไทยเกี่ยวกับบริการนี้ ได้จากพยาบาลหรือนักสังคมสงเคราะห์ ให้บริการฟรีและเป็นความลับ

Chúng tôi hiểu rằng việc chữa trị viêm gan C (hepatitis C) có thể là điều khó khăn, và chúng tôi có thể hỗ trợ cho bạn qua tiếng Việt. Hãy hỏi y tá hoặc nhân viên xã hội để nhận được thông tin Việt ngữ về dịch vụ này. Dịch vụ miễn phí và được bảo mật.

My story Ali

The seventies were pretty wild years for some of us baby boomers. I had a wide and eclectic circle of friends; musicians, artists, university students and school pals. All of us out and about discovering ourselves, pushing the boundaries and working out which direction to go in.

Forty years later and we're all spread across the world, with our different careers, jobs, lifestyles and financial backgrounds. We're a varied bunch! But there's one thing that many of us, even now, have in common: we're living with the hep C virus.

It was 2004 and I had been feeling very unwell and lethargic for many months before I finally sat in front of my GP and heard the news: "You have hep C."

I immediately entered a new world – I was referred to a specialist who treated me for a year while my health gradually worsened before sending me on to the liver clinic at RPA Hospital in Camperdown, Sydney. Things did not look good for me and my liver.

For ten years I went through the works: I had several esophageal bandings, and three severe internal haemorrhages (internal bleeding), which left me in induced comas, and fighting for my life. With low blood pressure, I regularly passed out, falling and breaking many bones. I spent most of 2012 in hospital or confined to bed, often with bouts of hepatic encephalopathy, where I was lucky to know who, where or what I was doing. And then the next development: liver cancer.

It was tough. I was a single mum with a young teenage son. And I had liver cancer. On June 28th, 2013 I received a liver transplant.

Recovering from a liver transplant is physically taxing, but even more so mentally, as your body reboots so do the mind and the spirit. And a new liver wasn't a whole new fresh start: I still had hep C.

Around six months ago, while I was still recovering, my hep C viral load started to spike. I was lucky enough to secure a spot in the sofosbuvir and ribavirin Gilead trial. After the third week, my viral levels had dropped low enough to be considered hep C clear and this amazing result continued. The side effects have been minimal and my treatment ended in February.

For the first time in 40 years I can say: I don't have hep C. It feels amazing.

Now that potential cures for just about anyone living with hep C have become a viable option, it seems morally and financially irresponsible to stall the process of delivering treatment, hope and a better life for all those, who are sick and waiting.

For myself - I'm back, healthy and hep C clear, with a positive and renewed energy and commitment. There is much hope in my life, and much hope for those looking forward to the availability of a treatment which must ultimately become available. It is most important that we continue to urge our government to make available a cure which is now within our reach. If you haven't yet got behind the EQUAL TREATMENT ACCESS campaign then I urge you to get involved so we can all work towards a world free of viral hepatitis.

I'd really like to thank Associate Professor Simone Strasser and RPA Liver Clinic professionals and staff.

Thanks for sharing your story, Ali (not pictured)

Hep Review magazine is a lifeline for many people, linking them to news, information, views and stories.

We want to hear from you about your story - together we'll share it with our community.

hepreview@hep.org.au

A YEAR OF LIVING BETTER

ometimes our lifestyle choices, such as alcohol, tobacco, drugs, sugar and fast foods are more unconscious habits rather than real choices.

For many of us, whether we are living with hep C or not, these habits can combine with a lack of exercise, stress and poor sleep to severely damage our health, giving us symptoms of tiredness, brain fog, depression, nausea and liver pain.

But we can change this!



Imagine making and sustaining 12 healthy habits in a year that last a lifetime.

A year of living better is a step-by-step series designed to help you achieve better health, in manageable chunks.

We propose taking your health into your own hands, by making one simple lifestyle change each month, sustaining that change and then the next month adding a new positive change.

All the changes are simple, low cost and require no expert or outside assistance. The ultimate goal of making healthy choices is to feel energised, focussed and full of vitality.

This first issue focuses on the basics of good nutrition, starting with how you eat to optimise digestion and then what you eat, looking at proteins, fats and vegetables.

After reading each section, decide what will inspire you and then write "My action" on your pull-out planner (pages 34-35) and then put your planner somewhere where you will be reminded of your choice.

March's "My action" has been filled in on the planner as an example.

AUTHORS

Ses Salmond has been in practice as a naturopath, herbalist and homeopath for over 20 years

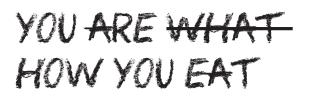
Ses was awarded her PhD from the School of Medicine and Public Health at the University of Newcastle in 2013 on the Hep573 Study, a clinical trial of silymarin alone and silymarin combined with antioxidants in the treatment of chronic hepatitis C.

She was awarded the Douglas Piper Young Investigator Award in Clinical Sciences by the Gastroenterological Society of Australia in 2010. She has been published widely in medical and naturopathic textbooks.

Rhoslyn Humphreys is a naturopath & medical nutritionist as well as a yoga & meditation teacher.

Rhoslyn holds a Bachelor of Naturopathy, an Advanced Diploma of Nutrition Medicine and an Advanced Diploma of Yoga.

Like to see the referenced version of this article? Email your request to hepreview@hep.org.au mages by Exposition by RAF



EAT MINDFULLY AND DIGEST YOUR FOOD WELL

7 Steps to mindful eating

Start by sitting at a table, away from distractions.

Take three, long, slow, gentle, deep breaths, breathing deep into the abdomen and up into the top of your lungs, exhaling slowly.

Slow down, as you eat, take breaks between mouthfuls, chew slower, breathe and assess fullness.

Become aware of the body's cues and use these cues to guide the decision to stop and start eating.

Acknowledge responses to food (likes, dislikes, neutral) without judgement.

Choose to eat food that is both pleasing and nourishing, using all of the senses while eating.

Be aware of the effects of eating out of boredom or sadness and overeating to the point of feeling uncomfortable.



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Do you gulp down your food without chewing much?

Do you feel bloated and uncomfortable after eating?

How about slowing down when you eat, and actually chewing, tasting and enjoying your food?

Mindful eating in scientific studies has been associated with improvements in well-being, self-esteem, optimism, reduced anxiety, weight loss and an overall increased satisfaction with life.

INCLUDE PROTEIN FOR REPAIR + SUSTAINABLE ENERGY



Protein is needed for growth and repair, liver detoxification, blood clotting, immune function, healthy blood pressure, blood acidalkali balance and the transport and storage of iron, cholesterol and other essential nutrients.

The liver makes the proteins that the body needs from the food that you eat.

When you have blood tests for a general check-up, take a look under the liver function section in your results. You'll find measures for certain proteins in the blood which indicate how well your liver is working (total protein, albumin and globulin).

If the liver fails to make proteins properly this can lead to serious health conditions with symptoms of excess bruising, abdominal distension, impaired immune function, anaemia and fatigue.

How much protein do you need?

Use the following examples as a general guide.

A woman who weighs 60 kg needs around 45 to 60 grams of protein a day

A man who weighs 80 kg would need around 60 to 80 grams of protein a day.

Athletes and people doing hard physical labour require slightly more protein for muscle development.

It is essential that everyone's diet contains adequate protein.

Most people should try and eat about between 0.8 grams to 1 gram of protein per kg of body weight per day.

If you are living with cirrhosis, you should aim to eat slightly more protein than this.

Check out the examples on the left as a guide.

EATARAINBOW OF SEASONALLY FRESH FRUIT AND VEGETABLES EVERY DAY

Aim to eat 5-7 serves of vegetables and a maximum of two serves of fruit every day for fibre and essential nutrients.

Local seasonal fruit and vegetables are fresh and cheap, frozen vegetables can also be great and very convenient. Try and eat a rainbow of coloured vegetables - red, orange, yellow, green, white and purple. The different colours in fruit and vegetables represent different nutrients, each with different benefits.

Most vegetables are high in anti-oxidants which are anti-inflammatory, anti-ageing and health promoting.

Vegetables are an important source of fibre in the diet. We need around 30 grams of fibre a day. A diet high in fibre and water will prevent constipation; reduce the risk of bowel cancer and promote the elimination of toxins, excess hormones and cholesterol.

Try a mix of roast root vegetables, to double your fibre intake (beetroot, sweet potato, parsnip etc) instead of pasta, rice or bread with your lunch, also great cold in salads.

See the Seasonal Food Guide for what is seasonal in your region.

seasonalfoodguide.com

Fruit and veg and whole grains are our main sources of fibre.

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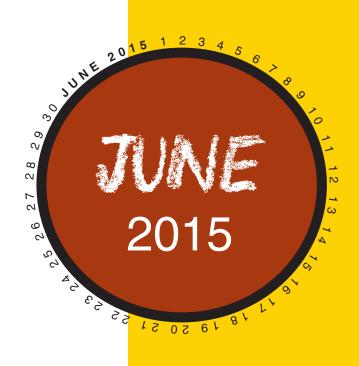
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It is quite difficult to achieve 30 grams of fibre a day. For example 4 heaped dessert spoons of oats for breakfast plus 1 cup of chopped broccoli with lunch plus 1 cup of rocket with dinner with an apple for a snack is only 13 grams of fibre a day!

Make sure you choose high fibre breads and cereals and that you add lots of high fibre vegetables to your meals.

There is no fibre at all in meat and fat.

FATS-BECOME A WELL-OILED MACHINE



Eating more carbohydrates instead of fats isn't healthy. Instead, increase vegetables, protein and good fats in your diet and reduce saturated fats, processed foods and carbohydrates such as sugar, fruit juice, soft drinks, bread, rice, white potatoes and pasta.

Avoid deep-fried food, fast food, potato chips, donuts, and poor quality meat pies and sausages. These foods tend to be high in trans fats, saturated fats, omega 6 oils, salt, sugar and low in fibre. They can lead to inflammation and pain in the body, and also tend to be very high in calories which can lead to weight gain.

When cooking, use fats that have a high burn point. Rice bran oil is great and can actually lower cholesterol.

Ideally our diet should have equal amounts of omega 3 and omega 6. However, we tend to have far too much omega 6 and too little omega 3 in our diet. This contributes to serious health issues such as cardiovascular disease and cancer. In one trial, patients with cardiovascular disease were given a diet with increased omega 3, relative to omega 6, resulting in 70% fewer deaths.

Great sources of omega 3 are oily fish such as sardines and mackerel or salmon. Flaxseed and walnuts are also good sources, as are game meats like kangaroo.

Olive oil is a "good" oil, add it to salads or drizzle on steamed veggies. It is a source of vitamin E, with 1 tablespoon (20 ml) giving you 10% of your daily requirement. In trials, vitamin E (natural) has been shown to be helpful in reducing fatty liver disease.

Fats to eat more of

Omega 3 is antiinflammatory and should be increased in the diet.

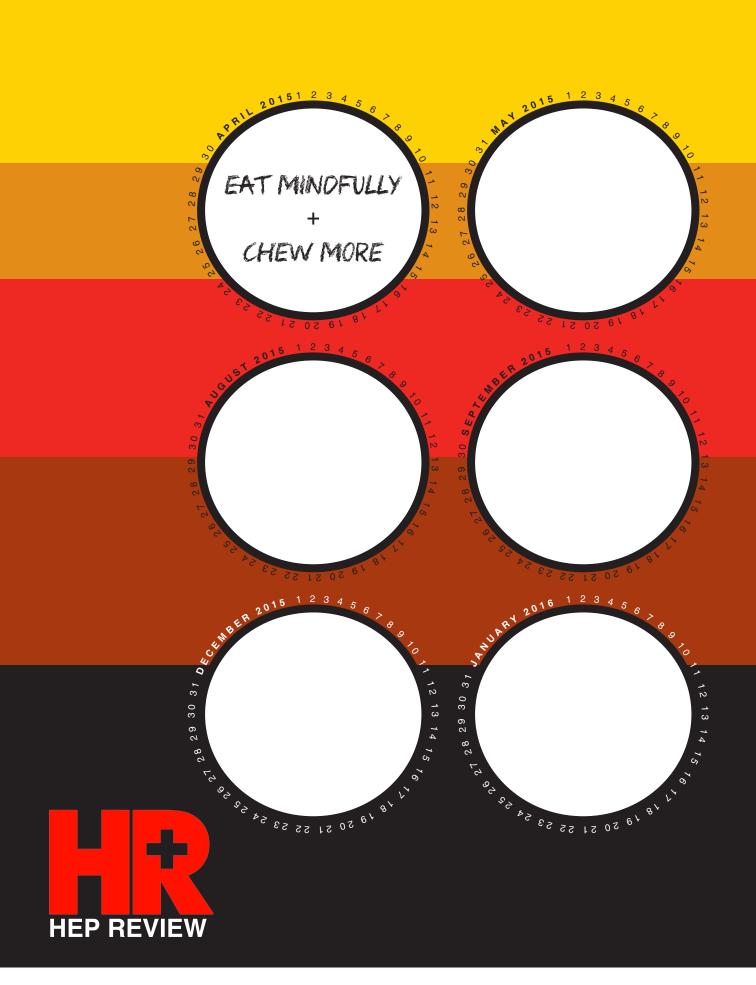
Good fats can also be added to the diet as whole foods, examples include fish, most nuts and seeds (walnut, pumpkin, almond, brazil, macadamia, flaxseed, sesame, tahini, sunflower) and some fruits and vegetables (avocados, coconut, olives).

Fats to eat less of

Omega 6 fats are not in themselves bad but are far too high in western diets and directly compete with omega 3 fats, causing inflammation.

Fats to avoid

Trans fats are to be avoided as they increase "bad" cholesterol and decrease "good" cholesterol, increasing the risk of cardiovascular disease.





hep.org.au / HEP REVIEW / 35

REMEMBER

Every meal should contain some protein.

This will help with weight management, as protein helps make you feel fuller for longer and will balance blood sugar levels, aiding restful sleep and repair. Reduced carbohydrate and adequate protein will also reduce the fat content in the liver.

Eat a rainbow of seasonally fresh fruit and vegetables every day.

At breakfast and lunch, aim for about a quarter of the plate protein, half the plate a variety of vegetables and a quarter of the plate carbohydrates and some good fats.

Always eat in a relaxed manner.

This will optimise digestion and maximise the benefit and the enjoyment of food.

In the next issue we will look at improving sleep, some breakfast ideas to set you up for the day and how to use fermented and bitter foods to improve your health further.

We've included four delicious recipes to help you include protein, vegetables and healthy oils in your diet on the next few pages.



Baked Salmon Steak

Ready in 30 minutes Serves 2

INGREDIENTS

- 2 salmon steaks, skin on, bones removed
- 2 dessert spoons of soy sauce or tamari sauce
- 1 whole lemon, juiced

METHOD

- 1. Preheat oven to 200 C.
- 2. Squeeze the lemon into a dish large enough to fit both salmon steaks, then add the soy/tamari sauce.
- 3. Place salmon in prepared dish. Turn it over once to ensure an even coating of the marinade.
- 4. Place each salmon steak into a separate tin foil sheet and create a rectangular shape around the base of the salmon with the foil. The purpose of this step is to ensure that a large amount of the marinade can be drizzled over the salmon steak so it has a 'poaching effect' when baking. This ensures that the meat is tender whilst still being cooked through.
- 5. Pour the marinade inside the foil over the salmon steak. Then finish wrapping the tin foil over the top of each steak so they are both completely covered.
- 6. Place the tin foil-covered steaks onto an oven tray and bake for 15 25 minutes at 180°C.
- 7. Take the salmon steaks out of the tin foil and serve with or without a dash of the marinade remaining inside the foil. *Hint* The marinade is also good to use over any vegetables you accompany the salmon with. Alternatively, a butter and lemon dressing also goes nicely with vegetables on the side.

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An- WAYNER

WHAT CAN YOU DO ABOUT DISCRIMINATION?

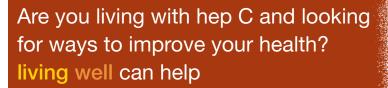
If you feel that you have been discriminated against or victimised, you can make a complaint to the NSW Anti-discrimination Board or the Australian Human Rights Commission.

Complaints of vilification can also be made to the Board.

HALC can provide you with legal advice and representation to help you with your complaint.

CALL 1800 063 060

HIV/AIDS LEGAL CENTRE www.halc.org.au



living well

living well is a free peer-facilitated program for people living with hep C run by people who have lived with hep C.

You will gain valuable knowledge, skills and resources on healthy living, self-managing your hepatitis and maintaining a positive lifestyle.

You will also learn how to set goals for your own health and get support to help achieve those goals.

If you or someone you know is interested in living well please contact:

Shae Clayton-Freedman Acting Programs Coordinator sclayton-freedman@hep.org.au 02 8217 7714

A YEAR OF LIVING BETTER

Here's a list of protein-rich foods (starting with the foods that have the most protein and working down).

Lean Meat: fish, chicken, turkey, beef, pork, kangaroo

Eggs

Nuts and seeds

Dairy: yoghurt – Greek, full fat with live cultures, cheese

Tofu, tempeh, edamame (fresh green soybeans)

Oats, wheat, barley, rye

Dried beans, chickpeas, lentils, split peas



Red Cabbage & Pear Salad

Ready in 10 minutes Serves 4

INGREDIENTS

- 1/2 red cabbage
- 1/2 a cup of walnuts
- 1 pear
- parmesan cheese
- olive oil
- balsamic vinegar

METHOD

- 1. Shred the cabbage.
- 2. Crush the walnuts.
- 3. Slice the pear into thin slices.
- 4. Rough grate the parmesan cheese (if you're using a 4-sided box grater, use the side that has three horizontal slices).
- 5. Toss the dry ingredients together, then drizzle with olive oil and vinegar.
- 6. Toss again, and serve.



Salt & Pepper baked cauliflower

Ready in 20 minutes Serves 4

INGREDIENTS

- 1 head of cauliflower
- 1 large clove of garlic
- coconut OR ghee OR rice bran oil
- salt and pepper

METHOD

- 1. Preheat the oven to 180°C
- 2. Cut the cauliflower into florets (the smaller pieces that make up the larger head of the cauliflower).
- 3. Dice the garlic
- 4. Place the florets in a roasting tray and drizzle with your oil
- 5. Sprinkle with salt and pepper and then toss the cauliflower with the diced garlic, so that the pieces get a light coating.
- 6. Place the roasting tray in the oven and cook for 15 - 25 minutes, stirring occasionally to ensure even roasting
- 7. Serve immediately



Roasted cauliflower with chickpeas, coriander and pomegranate

Ready in 20 minutes Serves 4

INGREDIENTS

- 1 head of cauliflower
- 1 large clove of garlic
- olive oil
- salt and pepper
- 1 tin chickpeas
- 1/2 bunch of coriander
- 1 pomegranate

METHOD

- 1. For the roasted cauliflower follow the recipe for Salt & Pepper baked cauliflower.
- 2. Chop the coriander
- 3. Cut the pomegranate in half and whack the outside with a spoon, dropping the segments into a bowl.
- 4. Drain the chickpeas and combine all ingredients in a large bowl.
- 5. Serve immediately. You could drizzle with balsamic vinegar for some extra kick.

Living with hep C 5:2 diet

at what you like for five days of the week, then let nothing but water pass your lips for the two other weekdays. That's the way this diet has been described in lunchrooms, on morning TV and in various articles for a while now. Sound dodgy?

In fact, it's a bit less extreme than that. Dieters are told to consume a 'normal' number of calories five days a week and then, for two, non-consecutive days, eat just 25% of their usual kilojoule/calorie total - 2100kJ/500 calories for women and 2520kJ/600 calories for men.



There are no restrictions on the types of food you can eat (though it's recommended and better – in terms of feeling full – to eat lower energy density, higher nutrient density foods on non-fast days rather than just having junk; lower carbohydrate foods are also recommended for fast days).

It's suggested that women can expect to lose about half a kilo a week on the diet, with men losing about the same if not a little more (so long as they don't binge on non-fasting days).

Of course, fasting (not eating for a period of time) has been around for a long time and there are theories (based on research using animals – mostly rats) - that this can be good for health and longevity. This research hasn't been replicated using human participants, and currently the general medical opinion is that the benefits of fasting are unproven and that until there are more human studies it's best to eat around 8700kJ/2,000 calories a day.

Any possible benefits to fasting are also likely to depend on a whole bunch of factors like whether or not you have diabetes, how old you are and how much exercise or physical work you do each day. And of course, whether or not you are living with hep C.





Images by Oscar Ramos

"Elige Vivir Sano" ("Choose healthy living") Government of Chile Agency: Lowe Porta

Pregnant and breast-feeding women, as well as people with diabetes, should seek medical advice before embarking on such a diet. Furthermore, this sort of diet can be unsafe for teenagers and children, who are likely to miss out on crucial nutrients needed for growth, and may be at risk of developing unhealthy eating habits. The 5:2 diet is also not suitable for anyone with decompensated liver disease, depression or a history of eating disorders.

The diet is tough. On fasting days you may feel low in energy, have poor concentration and could suffer headaches and dizziness – and you'll feel hungry!

If you do choose to follow the diet, make sure that your non-fast days are packed with nutritious options, including fruit, veg, whole grains and lean protein such as cottage cheese and dairy foods, lentils, eggwhites, chicken, or fish.

Please note, if you are considering attempting any form of diet please consult your doctor first to ensure you can do so without risk to health.

My story Zh

I had just started university and army training when I found out that I had hep B. It was 1994 and I was 18.

I'm from China originally, and I had been admitted to hospital because I had contracted hepatitis A. I can remember that they tested me then for hepatitis B as well, and I tested negative. Fast forward to a month after I'd left hospital and I now tested positive for hep B. At this time I had very little idea what that meant, but it quickly changed my life.

I'd been very active – I loved playing soccer, and I was a runner. My doctor told me that I risked serious health issues from organ damage if I exhausted myself physically. Goodbye soccer. Goodbye running.

I was also to find out that hep B was difficult to treat, especially at that time. The other thing I found out was that I had a much increased risk of developing liver cancer. Many more people are living with hep B in China than there are in Australia. I think in Australia there are about 210, 000 people who have hep B. In China that number is closer to 120 million people.

It was definitely difficult in the first few years – especially while I was living in China. A doctor had told me that hep B could be passed on by sharing food (it was a long time before I found out that this was NOT the case – hep B cannot be passed on by sharing food or even by kissing).

But at that time, it meant I adopted new eating habits – I would have two pairs of chopsticks: one pair to serve myself from the shared dishes on my family's dinner table, and the other pair to eat with. My family knew that I had hep B, so it was easy to do things like this. Outside of our Thanks for sharing your story, Zh

We want to hear from you about your story - together we'll share it with our community.

hepreview@hep.org.au

home it was more difficult – I would pass off my strange eating habits as being a personal quirk "It's just my way" I'd say, and people would accept that explanation. I was afraid of telling people because even though hep B is common in China, not a lot is known about it, so people can react badly because they don't know enough, and they're scared.

There were times when I was even more careful – especially if my ALT levels were up. This tends to correspond with increased levels of virus in your system, so it's at those times that it can be easier to pass the virus on.

Treatment for hep B is quite complicated. It's different to hep C, because whether you take treatment or not depends on how the virus is behaving. In 2002, I had a bad experience of hep B treatment in China; it was expensive – more than I could easily afford – and I had no proper clinical supervision. This was a bad time for me.

It happened because the company I was working for at the time was allowed to access my blood-test results. Once they discovered that I had hep B they demanded I take treatment. These days that's illegal in China, but then it was allowable. Having had professional treatment in Australia, I can now say that this wasn't really 'proper' treatment – my health wasn't monitored properly, I had to give up the treatment and I was left to deal with the side-effects as best I could.

I was depressed and I didn't want to leave the house. But as a man in China, there's a lot of pressure not to show any signs of weakness. "Weakness" meaning: not a man's behaviour. It was a really hard time for me and it really affected my self-confidence. I kept up my "I'm fine" face in public, but inside and at home it was a dark and lonely time.

That was then, this is now. I'm 38 and I'm healthier than ever. I think of hep B as having been the single greatest motivator for me to look after my health. I don't drink alcohol, I don't smoke. I maintain a healthy lifestyle. I've started running again.

I tell people about my hep B when I have to. I'd say over 90% of the time this works out fine – people respect that I'm being open with them. Mostly partners have either already been vaccinated for hep B, or they've gone and had a check to find out whether or not they're already immune and then get vaccinated based on that.

For me, hep B means I know just how important good health is – what a gift our bodies are, and that they're a great return on investment! Look after your health and body and they'll be much better able to look after you in turn.

The other difference between then and now is that I now have doctors I trust, who know what they're doing. I recently had a viral 'flare' (the amount of virus in my system increased dramatically) and my clinic was onto it right away. I'm on treatment again at the moment, to keep the virus from damaging my liver. It's one pill a day, which is a small price to pay for ` better health.

The search is still on for a cure to hep B, and I've taken part in treatment trials to try and get rid of my hep B once and for all. For now, I'm still living with the virus, but it's undetectable. I feel lucky to have great doctors and clinic nurses, and to feel in charge of my own health. "I think of hep B as having been the single greatest motivator for me to look after my health."



he number of people accessing NSPs who use performance and image enhancing drugs (PIEDS) is on the rise. 2013's National NSP Survey put numbers to this (showing an increase from 2% of NSP clients reporting PIED use in 2009 to 7% in 2013) and the feedback from frontline NSP staff indicates that this trend shows no sign of decline.

In Canterbury, Mission of Hope (a Muslim not for profit health organisation), with the support of the Inner West Sydney Medicare Local, has partnered with Sydney Local Health District and Hepatitis NSW's *Going Viral* to ensure this growing group of NSP users in their area are as hep C aware as other groups who have traditionally accessed NSPs.

Going Viral training for Muslim youth workers

May 2014: SLHD and Hepatitis NSW trained young men at Hayat House Street Outreach as safer PIED-use mentors. Mentors were equipped with the knowledge and skills to promote safer injecting practices and NSP referral. Hayat House Street Outreach is a branch of Mission of Hope specialising in mentoring, referrals and outreach to young at-risk men in the Canterbury-Bankstown LGAs.

Social media awareness campaign & Short film

A campaign with a focus on hep C, safer injecting and NSPs will launch soon on Facebook and Twitter as well as in gyms in the Canterbury-

Maliora

"Reassuring to hear a sheikh speak about harm minimisation and its permissibility in Islam. I feel more confident to discuss these with my nephews in my personal time, as well as with my patients."

> Going Viral/Mission of Hope Community Forum participant

Bankstown area. Five gyms are already interested in getting behind the campaign.

Young PIED users often have a profound respect for sportspeople like NRL players and boxers. With this in mind, local sports celebrities are coming on board to inform and promote safer injecting practices, NSPs, and hep C awareness via the film and campaign.

Mission of Hope has had an overwhelming response to this campaign, with support coming from community organisations, religious leaders, parents and social workers.

A two-part community forum for parents and health professionals

August 2014: an all-day community forum was held in Bankstown. It was an opportunity for the community to address issues that affect many people, but are rarely openly discussed - the reality of drugs, alcohol and sex-work in the Muslim community, sexual health, harm minimisation and the experience of Muslim people in prison.

Twelve (12) Muslim speakers were engaged to provide expert information and community insight. They came from a range of backgrounds including social research, the medical profession, allied health professionals and social workers. Over 100 people attended, with 100% of attendees said that they would attend a similar event again, and that they would encourage their friends and family to attend.

Mission of Hope plans to hold the forums on an annual basis.



RESEARCH INTO VIRAL HEPATITIS

POTENTIAL CURE FOR HEP B BEGINS HUMAN TRIAL

Hep B is a viral disease that infects liver cells. Although a vaccine has been available since 1982, more than two billion people worldwide have been infected with the virus at some point during their lives. Most patients will recover from the disease, but 5-10 per cent of patients will develop a chronic infection, with children most at risk. More than 780,000 people die every year from complications associated with chronic hepatitis B infection. including cirrhosis and liver cancer.

The new treatment uses TetraLogic Pharmaceutical's drug birinapant, which triggers the breakdown of proteins that prevent infected cells from selfdestructing. Dr Mark Pellegrini said these proteins, known as 'inhibitors of apoptosis proteins' (IAPs), can be targeted to allow infected cells to die.

"Our preclinical models have shown that birinapant kills infected liver cells, while not harming uninfected cells," he said. "Used in conjunction with an existing treatment for hepatitis B, this drug has the potential, for the first time, to functionally cure chronic hepatitis B infections."

Dr Pellegrini said the new treatment had the potential to revolutionise the way chronic hep B infections were treated. "Patients who develop chronic infections can be treated with drugs that prevent the virus from replicating, reducing the amount of virus in the liver, but do not completely eliminate the virus," he said.

"These patients are dependent on anti-viral drugs that need to be taken for a very long period of time to reduce the risk of virusinduced liver damage and the complications that come with it.

"Our new therapy combines an existing anti-viral drug, which reduces the viral load, with birinapant that promotes efficient killing of hepatitis B infected cells and clearance of the virus from the system."

"We are really excited that this treatment has entered phase 1/2a clinical trials as it is a culmination of many years work in developing new strategies to tackle chronic infections."

Based on his crucial research, Dr Pellegrini is the key scientific and clinical advisor for the clinical study that is now underway. The study is sponsored by TetraLogic Pharmaceuticals Corporation in collaboration with Nucleus Network in Melbourne and hospitals across Australia and New Zealand.

The phase 1/2a clinical trial will involve approximately 50 patients and is currently recruiting eligible participants. The clinical trial will be held at sites across Australia and New Zealand, with planned sites in Melbourne, Adelaide, Perth and Auckland.

Interested? Contact the Hepatitis Infoline 1800 803 990 for information about recruitment to this hep B treatment triall. Ed

Abridged from wehi.edu.au

NEW LIVER TRANSLANT RECIPE FOR SUCCESS

A new preservation system that pumps cooled, oxygen-rich fluid into donor livers not only keeps the organs in excellent condition for as long as nine hours before transplantation, but also leads to dramatically better liver function and increases survival of recipients, according to a series of animal studies by researchers at the University of Pittsburgh School of Medicine and the McGowan Institute for Regenerative Medicine. The system could be tested with transplant patients later this year.

Currently, 20 to 40 percent of donor livers cannot be transplanted into recipients because oxygen deprivation during storage and transport in conventional containers can make pre-existing tissue damage worse, explained senior investigator Paulo Fontes, M.D. If the damage is too extensive, the organ cannot be safely transplanted into a patient.

"Standard practice is to use a method called cold static preservation, which uses tissue cooling to slow down metabolism with the aim of reducing the demand for oxygen and thus protecting cells from death," Dr. Fontes explained. "In our new system, we pump a special fluid designed to deliver oxygen to the liver, creating an environment that supports normal function. The integrity of the cells and vital metabolic activity is sustained for eventual transplantation of the organ."

The team transplanted six pigs with livers that had been kept for nine hours, roughly the average time between recovery of the organ and transplantation into a recipient, in the MP system and another six with organs placed in the standard container. They found that 100 percent of the pigs who got MP livers survived, compared to 33 percent of those who received conventionally preserved organs. The MP livers functioned better, produced more bile and had higher oxygen levels than their conventional counterparts, and analyses of multiple biomarkers including inflammatory mediators indicated that the MP livers had been better preserved.

Abridged from prweb.com

Questions? Head to HepNSW Online Forum



A place to connect

related to viral hepatitis.



This is a forum where you can discuss issues

Whether you are a health worker or someone affected by viral hepatitis, you are welcome to join this forum.

www.hep.org.au/forums/

"It's so much better to talk to someone than bottling it all up inside, especially if you are on treatment."

"HepConnect definitely helped me, and I am motivated by other people who have been through the treatment."

"I like being able to help people who are going through what I've been through, I wish *HepConnect* was around back when I was on treatment."

> "Throughout my 24 week treatment she was the only person I had contact with that had hep C. It meant so much to me to actually speak to another person who has been affected by hep C."



Hep Connect treatment peer support 1800 803 990 Extracts from

A Study of Aboriginal people in NSW living with hep C

from the Centre for Social Research in Health

Carla Treloar Clair Jackson Hannah Wilson Veronica Saunders Loren Brener Priscilla Johnson Jamee Newland Rebecca Gray

Hep C diagnosis and percieved stigma

Participants spoke about the impact of diagnosis on their feelings. For some people, diagnosis was given with litle or no other information.



I AM VERY CAREFUL WHOM I TELL THAT I HAVE HEP C



agreed or strongly agreed

agreed or

strongly

agreed

MOST PEOPLE BELIEVE I AM DIRTY BECAUSE I HAVE HEP C



I FEEL SHAME BECAUSE OF MY HEP C I WORRY THAT PEOPLE MAY JUDGE ME WHEN THEY LEARN THAT I HAVE HEP C



"I was shattered, I felt dirty ... I still to this day haven't really, I haven't told any of my family, haven't told anyone you know... I have just kept it to myself."

44 years old, currently on hep C treatment

Resilience

Resilience is a measure of how people feel they are coping with the hard times in life. Understanding resilience is important to understand living with hep C.

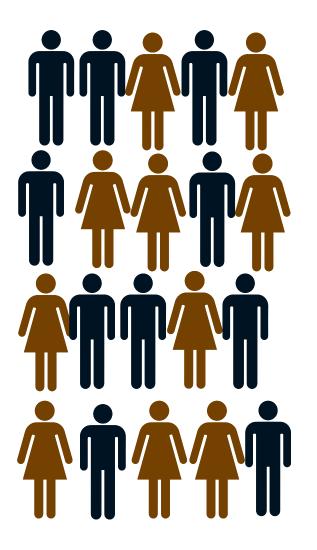


"I always went on the fact that as long as I look after my liver I will be alright, so that was when I went nil alcohol or anything to make sure my liver was strong – I sort of took treatment on myself. I always had healthy vegetables, I had a fairly good diet but yeah, I don't know I just sort of opened my eyes a little more, like I am not superman."

45 years old, completed hep C treatment

Lifestyle changes

Since being diagnosed with hep C . . .





of people said they changed their diets



said they had hep C check-ups more regularly



said they had cut down or cut out alcohol



said they had cut down or stopped illicit drug use



said they had accessed info about hep C and hep C treatment



said they had increased their level of exercise

People living with hep C need to be treated with respect by health workers, and without stigma or discrimination.

- Overall findings, A Study of Aboriginal people in NSW living with hep C

For the full report visit csrh.arts.edu.au/research/projects

Looking for information about clinical trials for new and developing treatments?

>>>

PLUS check out HepNSW Forum for discussions and updates about research, trials, campaigns and community events

hep.org.au/forums/

CLINICALTRIALS.GOV

Clinicaltrial.gov is another US-based database of most of the clinical trials that are happening all over the world, including Australia.

To find what you need, you can use the homepage search bar, and enter your search terms eg. "Hepatitis C" and "Bathurst".

You can also use the Advanced search to narrow down your search results, so that you only see studies that are currently recruiting participants, for example.

CENTERWATCH.COM

Centrewatch.com is a US-based database of clinical trials. CenterWatch provide patients and their advocates information on clinical trials, specific drugs, as well as other essential health and educational resources.

- Search clinical trials
- Receive email notifications about specific
 clinical trials
- Review results from completed clinical trials
- Search drug information
- Learn about volunteering for a clinical trial
- Learn about the informed consent process
- Read an overview of the clinical trials process
- Find disease-specific health associations and other educational resources

RESEARCH

Studies currently recruiting people living with hep C

THE HEPATITIS C TREATMENT OUTCOME STUDY www.hcvstudy.bond.edu.au

You are invited to take part in a study designed to determine some of the physical, psychological, and social factors associated with hep C treatment outcomes.

Previous research has indicated that certain physical and psychological profiles predict better treatment outcomes across a range of medical conditions. Little is known of how these factors predict treatment outcomes in hep C.

LIVER HEALTH PROJECT

ALL SO STATES

People living with hep C in Australia are invited to take part in a study about the experiences of living with hepatitis over time, including disclosure, well-being, employment, discrimination, stigma and resilience. The study will also look at people's responses to the rapidly changing treatment environment, and subsequent shifts in their experiences at clinics and with their healthcare providers and aims to identify the current and future support and service needs of people living with hep C.

You will take part in three confidential research interviews. To take Contact Jeanne Ellard part you must have been diagnosed with hep C, live in Australia and be over the age of 18.

A PARTY AND A PART

The primary objective of this research is to increase understanding of individual profiles that are associated with better Hepatitis C treatment outcomes.

Contact Simon Langston **Bond University** slangston@bond.edu.au

Each interview will take approximately one hour and can be conducted face-toface if you live in Sydney or over the telephone at a time convenient to you. You can be reimbursed up to \$50 per interview.

La Trobe University 02 9385 9496 or J.Ellard@Latrobe.edu.au

BETTER TESTING: RESPONDING TO CHRONIC HEP B www.latrobe.edu.au/arcshs/surveys/better-testing

La Trobe University researchers are recruiting people who have been diagnosed with hep B in Australia to talk about when and how they were diagnosed. This research aims to improve the kinds of information and support people receive when they are first diagnosed.

Participation includes a 30 minute phone interview. Participants who wish to be interviewed in a language other than English may request the presence of a translator.

Participation will be kept completely confidential. There is a \$20 gift in appreciation of participation.

Image by Exposition by RAF

To take part in an interview, participants must be 18 years or older and have been diagnosed with hep B in Australia.

Contact Duane Duncan d.duncan@latrobe.edu.au or Jack Wallace j.wallace@latrobe.edu.au

OPINION

Expensive medicines: ensuring objective appraisal and equitable access

Bulletin of the World Health Organization 2015; 93:4

Suzanne R Hill a, Lisa Bero b, Geoff McColl a & Elizabeth Roughead c

a. University of
Melbourne, Australia.
b. Charles Perkins
Centre, University of
Sydney, Australia.
c. University of South
Adelaide, Australia.

In response to requests for the funding of new drugs, reimbursement agencies are re-evaluating some of the methods used in assessing these products. Many trials submitted for the regulatory review of new drugs do not provide adequate data for subsidy decisions.

We argue that all involved in bringing medicines to market need to be explicit about the additional information required, decide how these data should be collected and assessed and the methods that should be used to set a fair price for a new drug.

In Australia, a formal appraisal of the cost–effectiveness and budget impact of a new medicine precedes any subsidy decision at national level. If a new product is subsidised, the government pays an agreed price to the manufacturer, sometimes with requirements for financial contracts to manage expenditure.

Increasingly, patients are asking for early access to new drugs, particularly for treating cancer. In consequence, strategies to subsidise drugs for use under conditions of coverage with evidence development or managed entry are being proposed. A new drug might be approved even if there is no evidence to show that it satisfies the standards typically applied in health technology assessments.

However, this approval is often contingent upon additional requirements for subsequent randomised trials or the collection of data on the drug's effectiveness and safety in practice. There is no consensus on the best methods for identifying drugs appropriate for managed entry schemes, for collecting post-approval data or for the use of such data to modify decisions about coverage. In Australia, as in many other countries, several questions need to be answered. Can stakeholders produce a workable framework for managed entry schemes? What can be done to reduce variation in the inputs used for cost-effectiveness models? How can drug or disease registries contribute useful information to inform reimbursement decisions? How should registry data be evaluated? What can be done to make registry data more representative of the population and what types of post-progression data should be included in trials of targeted cancer therapies?

Regulatory agencies, insurers and clinicians also need to be able to determine if a new drug represents good value for money and what to do if an effective drug appears too highly priced for the benefit that it offers. The prices of several recentlyintroduced drugs – for example aflibercept, ivacaftor and sofosbuvir – have been questioned.

The way in which drug prices change over time has generally been a function of the market. Typically, a new drug is launched under patent and can command a good price until the patent expires and competition and/or generic products emerge. Exceptionally, public pressure and legal challenges decreased the price of several antiretroviral drugs in countries with high burdens of human immunodeficiency virus before patent expiry.

Other strategies, such as compulsory licensing, have had limited success. Tiered pricing has also been proposed but defining each tier and an appropriate price for each has proved challenging.

The recent approval of high-priced medicines for many conditions has prompted a new round of discussions and calls for radical changes to the current commercial model for drug development. We consider that it is time for a global forum to discuss objectivity and equity in access to high-priced drugs.

Such a forum should extend beyond the usual networks of payers and authorities on health technology assessment. It needs to define the methods needed to manage the early entry of promising products – i.e. how to evaluate the data that are available for early market entry, determine an appropriate initial price, optimize the collection of data from clinical practice, enable independent trials and manage the exit of products that, in practice, are found to be insufficiently effective.

The forum should promote the development of a method for pricing new drugs. Such a method needs to reconcile the need for fair pricing, with the difficulties of obtaining accurate information on research, development and manufacturing costs. The forum should include representatives of patient and consumer groups, so that the right questions are asked, appropriate research priorities are set and outcomes are communicated. In managing access to new drugs, simply continuing to react countryby-country and disease-by-disease is not sustainable.

We need to be more forwardthinking and take some of the pressure off small purchasers and countries that are currently trying to make equitable decisions in isolation.

We need to solve the fundamental problem of how to balance objectivity of appraisal and equity in access to new products; ensuring that medical advances are affordable, working with a viable pharmaceutical industry that responds to public health needs. Have an opinion on this? Join the conversation.

Twitter@ hepatitisnsw

Facebook Hepatitis NSW

HepNSW Forum







Have the chat that saves lives. Discover, Decide, Discuss organ and tissue donation today.

donatelife.gov.au

ARIES

This is a good time to take stock of where you're at: throw out anything in your fridge that remembers 90s fashion from the first time around.

HORRORSCOPE

Remember - dogs can be a man's best friend or a woman's best friend. They could also be a child's best friend, or a cat's best friend. Dogs are totally flexible. Take a lesson from dogs.

TAURUS

Romance is in the air today, just over the Kakadu national park. If you don't happen to be in the Top-End then chances are you're going to strike out again throughout this month.

But life can be as romantic as you wish to make it. Why not give yourself a big hug? A good time to try this is at the start of a presentation to your co-workers.

Gemini

When your lover starts wearing more clothes to bed than to work, it's a good guess that your happiness is close to being over. This month will see you take up competitive knitting.

You'll enjoy the benefits of your position this week when you chuck a sickie. It would be bad luck to post pics of yourself on waterslides on social media that day.

Leo

Three times a lady is a hell of a lot of lady, you might think. But later on this month you might find yourself thinking "Well, now that just seems like a fairly standard amount of lady". And if you think that, well then I will have done my job.

VIRGO

You'll bump into an old flame this month. The reasons things burn for a long time are usually a) they're mythical birds OR b) they're toxic fossil fuels. If you decide to go there anyway, fine. It's your bonfire.

Instead, choose a new hobby. Scrap-booking will prepare you well for when you can no longer make conversation about anything but cats, cardboard cutouts and grandchildren.

LIBRA

Only love can break your heart...but trans-fatty acids will also have a damn good try.

Resist the urge to steal at the self-serve supermarket checkout. They are watching.

SCORPIO

You're the most romantic of all the signs, Scorpio, so chances are you're seeing someone. Be careful when talking about this relationship: Significant other, or S.O., is a fairly disturbing way to refer to a loved one. Why not call them "that thing I know" or "unstranger"? You silver-tongued devil!

SAGITTARIUS

You've been thinking that 2015 will be "your" year. This basically just shows how self-involved you are.

Work on your fear of cats and other small predators. This will help when you are eventually set-upon and eaten by a pack of wild siamese kittens while walking home from work.

CAPRICORN

Have you ever not known how to tell someone that they have some snot hanging out their nose? That's how I feel about your forecast this month.

Try to keep your head down – you might find two-dollars.

AQUARIUS

Stop resisting change - your sheets needs a wash. You have more than bacteria to contribute to civilisation.

Be kind to yourself - it will set a good example for others.

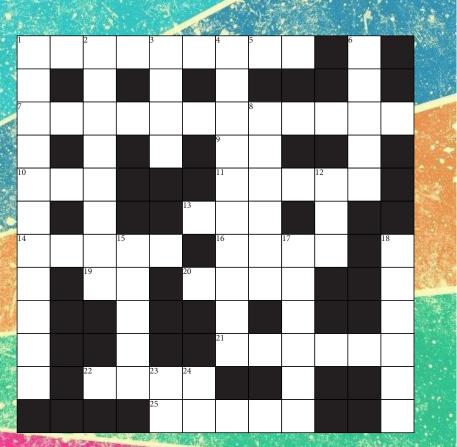
PISCES

The number 10 may be given added significance today and will randomly pop up in everyday conversations. 10.

Three is the magic number because some people have a magic superfluous nipple which can change the colour of the sky.

10.

CROSSWORD





ACROSS

1. 'SVR' stands for '_ Virological Response' (9) 7. A vaccine is designed to be '_' rather than curative (12) 9. This kind of light can damage your skin (2) 10. Slang word meaning 'cool' or 'awesome' (3) 11. '_' response to treatment. Quick. (5) 13. Slang term for marijuana (3) 14. Burn something a little (5) 16. Sheet of window glass (4) 19. Green means '_' (2) 20. Hepatitis NSW have asked political parties to commit to improving hep C '_' (4) (pg.10) 21. Crowd together; nestle closely (6) 22. A long time; It is taking '_' for new hep C treatments to be funded in Australia. (4) 25. Slept lightly (5) DOWN 1. Viral '_' is the goal of treatment for hep B (11) 2. Government '_' on new treatments would be a good return on investment. (8) 3. Film: Planet of the '_' (4) 4. Alternative medicine practioner (10)6. Rescued (5) 8. An icon or figure representing a person in a computer game (6) 12. Anger (3) 15. NSW hep C prevention project: '_' Viral (5) 17. Necessary (6) 18. Legal right to exclude others from making, using, or selling an invention. (6) 23. Newspaper boss (abbr.) (2) 24. Therefore (2)

Find solutions to Hep Review crossword at hep.org.au

MONITOR MANAGE T R E A T

CLINIC HIGHLIGHT

Hunter New England Local Health District Liver Clinics (02) 49213478

HNE Liver Clinics provide culturally appropriate and friendly services.

They provide education and information on viral hepatitis and access to hepatitis treatment.

They also provide information and support to patients preparing for treatment, supportive counselling during all stages of treatment, ongoing case management and health monitoring in relation to liver care.

CLINIC	CONTACT	SE	SERVICES			
The Albion Centre Surry Hills	9332 9600	С	B *friday:	F* s only		
Bathurst liver clinic Bathurst Hospital	6330 5346 0407 523 838	С	В	F		
Bega District Hospital Interferon Treatment Unit	6492 3255	С	В			
HEPATITIS INFOLINE 1800 803 990 INFO, SUPPORT, REFERRALS						
Burwood Endoscopy Centre	9745 3988 endoscopy@iinet.net.au	С	Treatme Banksto Outpatie	ent through wn Hospital ents Clinic		
Canberra Gastroenterology Hepatology Unit	6244 2195	С	в	F		

Canterbury Hospital – Outpatients Liver Clinic	9767 6372 legan@ med.usyd.edu.au	С			
Coffs Harbour Base Hospital – Hepatitis Treatment Unit	6652 5655	С		F	
Coffs Harbour Sexual Health Clinic 916	6656 7865	С	В	F	
Concord Hospital – Liver Clinic	9767 8310 melissa.kermeen@ sswahs.nsw.gov.au	С		F	

C - Hep C treatment & monitoring B - Hep B treatment & monitoring F - Fibroscan

MONITOR MANAGE TREAT

CLINIC HIGHLIGHT

Hunter New England Local Health District Liver Clinics (02) 49213478

HNE Liver Clinic Locations

John Hunter Hospital - New Lambton

Tamworth

Newcastle

Cessnock

Raymond Terrace

Taree

CLINIC	CONTACT	SEF	RVICES		
Central Coast Hepatitis C Clinic	4320 2390 helen.blacklaws@ health.nsw.gov.au	С	B F* *two days/month		
Centre for Addiction Medicine, Westmead	9840 3462	с	B F		
Clinic 16 Royal North Shore Hospital	9462 9500	С	B F		
Clinic 33 Port Macquarie Community Health Centre	6588 2750 hdc@midcoast.com.au	с	B F* *one day/month		
Eastern Suburbs Endoscopy Centre Bondi Junction	9387 6600 paullgoodman@ gmail.com	с			
Excel Endoscopy Centre, Campsie	9718 0041 excelendocentre@ gmail.com	С	В		
Gosford Hospital – Endoscopy Unit	4320 2111	С	B F* *one day/month		
Gosford Hospital – Teaching & Research Unit (Wyong)	4320 2390	С	B F* *one day/month		
Goulburn Community Health Centre	4827 3913	С			
Holdsworth House Medical Practice – Byron Bay/Sydney	6680 7211 (Byron) 9331 7228 (Sydney)	С	В		

 ${\bm C}$ - Hep C treatment & monitoring $\,{\bm B}\,$ - Hep B treatment & monitoring $\,{\bm F}\,$ - Fibroscan

	C - Hep C treatment & monitoring B - Hep B treatment & montioring F - Fibroscan				
MONITOR MANAGE TREAT	CLINIC	CONTACT	SEF	RVICES	
	John Hunter Hospital – Hepatitis Service	4921 3478	С	F	
	Kirketon Road Centre (KRC) Kings Cross	9360 2766 phillip.read@sesiahs. health.nsw.gov.au	С	B* F *one clinic/month	
	Lidcombe Hospital – Outpatients Liver Clinic	9722 8400	С		
	Lismore Liver Clinic	6620 7539 mark.fuller@ncahs. health.nsw.gov.au	с	B F	
	Liverpool Hospital – Department of Gastro & Hepatology	8738 4074 miriam.levy@ sswahs.nsw.gov.au	С	B F	
MY	Manning Clinic Taree Community Health	6592 9315 n Centre	С	B Treatment referred to Newcastle	
	HEPATITIS INFOLINE	1800 803 990 INFO, SUP	PORT	, REFERRALS	
	Narooma Community Health Centre	4476 2344	С		
	Nepean Hospital Outpatients	4734 3466 vincenzo.frageomeli@ health.nsw.gov.au	С	B F	
	Nepean Private Specialists Centre	4722 5550	С		

MONITOR MANAGE TREAT

Is your hepatitis clinic or treatment centre located in NSW but not listed here?

Contact us with the details and we'll add you to our clinic directory!

C - Hep C treatment & monitoring B - Hep B treatment & montioring F - Fibroscan						
CLINIC	CONTACT	SERV	/ICES	6		
Northern Rivers Gastroenterology Lismore	6622 0388 nrgstaff@tpg.com.au	I C	В			
Orange Interferon Treatment Unit Orange Community Heal	6392 8600 th Centre	С		F		
Orange Base Hospital	6369 3000	С		F		
Prince Of Wales Hospital Liver Unit	9382 3100 cherie.raby@ sesiahs.health.nsw.go	C v.au	В	F		
Royal Prince Alfred Hospital AW Morrow Liver Clinic	9515 7268	С	В	F		
St George Hospital – Hepatology & Liver Clinic	9113 3111 Lisa.Dowdell@ sesiahs.health.nsw.go	C v.au	в	F		
St Vincents Specialist Medical Centre Lismore	6622 0388 nrgstaff@tpg.com.au	С	В			
St Vincents Hospital – Viral Hepatitis Clinic	8382 3707 viralhepatitis@ stvincents.com.au	С	В	F		
Sydney Clinic for Gastrointestinal Diseases	9369 3666	С	в			
Wagga Wagga Hospital Hepatitis Treatment Unit	6921 2711	С		red to te rooms		

C - Hep C treatment & monitoring B - Hep B treatment & monitoring F - Fibroscan

MONITOR MANAGE T R E A T

C - Hep C treatment & monitoring B - Hep B treatment & montioring F - Fibroscan						
CLINIC	CONTACT	SERVICES				
Westmead Childrens Hospital	9845 3989	С	В			
Westmead Drug and Alcohol Services	9840 3462	с		F		
Westmead Gastroenterology Hepatology Department	9845 7705 jacob_george@ wmi.usyd.edu.au	с	в	F		
Wollongong Hospital Hepatology Unit	4222 5180	с	в	F		

Check out our online hepatitis service directory at hep.org.au

In prison but want to get treated for hep C?

You need to make an appointment to see the nurse at your Centre and tell them that you would like to be treated for hep C.

It may take some time – they will do some preparation work to find out which treatment is best for you – after that you will join the waiting list for treatment.

You can find out more about treatment by calling the Hepatitis Infoline - dial number 3 on the common calls list.

Enter to WIN a \$100 Coles/Myer gift card!

It's easy! Just give us your feedback to help us develop a better magazine. For each edition we draw one winner from all entries received who have provided a name and contact number. Draw entry open to NSW residents only. Limit one entry per person.

Fill out the survey on this page and the next OR go to https://www.surveymonkey.com/s/HepReview

TO SEND

- 1. Fill out the survey
- 2. Carefully rip or cut out this page
- 3. Fold the top part of the page back along the top dotted line
- 4. Then fold this bottom part back along the bottom dotted line
- 5. No one will be able to see what you've written
- 6. Secure the top back edge (the shaded bit below) with sticky tape
- 7. Post the form in your nearest mailbox
- 8. Or fax both sides of this form to 9332 1730

Delivery Address: PO Box 432 DARLINGHURST NSW 1300



HEP REVIEW	1.	After reading this edition of <i>Hep</i> <i>Review</i> magazine, I feel I know more about hepatitis	Strongly Agree	Neither	Disagree	Strongly disagree
	2.	l know more about keeping healthy with hepatitis	Strongly Agree agree	Neither	Disagree	Strongly disagree
CONTACT	3.	I think this magazine is useful to me	Strongly Agree agree	Neither	Disagree	Strongly disagree
DETAILS FOR GIFT	4.	How do you think we could make Hep Review better?				
CARD PRIZE DRAW	5.	Since reading this edition of Hep I have called the Hepatitis Infol I have looked up the (www.hep. I feel more connected to a com	line org.au) website			
		I have phoned one of the clinics	s listed in the maga	zine		
		I have talked to someone else a				
ber		I have changed my lifestyle (wh Other - please tell us below	at I eat or drink, or	how much	l exercise)	
Name t number act email						
Name Contact number OR Contact email						

Thanks for your feedback! Congratulations and thanks to S.Z- winner of \$100 gift card for Edition 86

If you have other feedback about Hep Review email hepreview@hep.org.au

6

YOU MIGHT NOT KNOW IF YOU HAVE HEPC

The only way to really find out is to have a hep C PCR test (A test for hep C antibodies is not enough)

HEPATITIS INFOLINE 1800 803 990 INFO, SUPPORT, REFERRALS

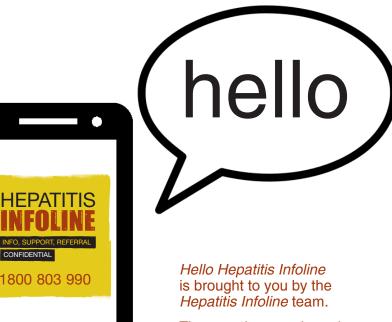




Hepatitis NSW Working towards a world free of viral hepatitis

Printed FEB 2014

www.hep.org.au



The questions are based on real-life calls but details have been changed to protect caller's privacy.

ello Hepatitis Infoline. I've just been on holiday and I think I may have been exposed to hepatitis B.

What could happen to me?

Graham, 34

Hi Graham,

If you've been exposed to hep B and have not been vaccinated then you could develop acute hep B. You could then go on to have chronic hep B.

The chances are that this won't happen – nine out of 10 adults exposed to hep B clear the virus within six months. These people will then be immune to hep B (they won't get hep B again).

A further 5 out of 100 adults exposed to hep B will clear the virus within 12 months. These people will then be immune to hep B (they won't get hep B again). For people living with chronic hep B, there is very effective treatment to help manage their hep B.

People living with chronic hep B should see their doctor and have a liver health check every 3, 6 or 12 months depending on how their liver is doing. This will help decide whether treatment is required. Liver damage from hep B can change over time and may cause no symptoms so regular checkups are really important.

To find out more about treatment for hep B check out our hep B treatment section at www.hep.org.au or call the *Hepatitis Infoline* 1800 803 990.

Have a question for Hello Hepatitis Infoline?

Send your question to email@hep.org.au or call the Hepatitis Infoline on 1800 803 990

Like Hep Review?

Yes! (We hope)

And we want to keep you happy!

We're changing the way membership works at Hepatitis NSW to make it more relevant to our communities.

It's now FREE for people living with, or with lived experience of, viral hepatitis in NSW and we have great membership deals for professionals, organisations and people in other states & territories, too.

You'll be able to use our new website to renew and update your details and keep your subscription current for *Hep Review* and our other great resources.

We'll be writing to or emailing you soon to let you know all the details. HEP REVIEW JULY - OCTOBER 2015 edition 88

HEP C HOLIDAY Travel as a treatment option

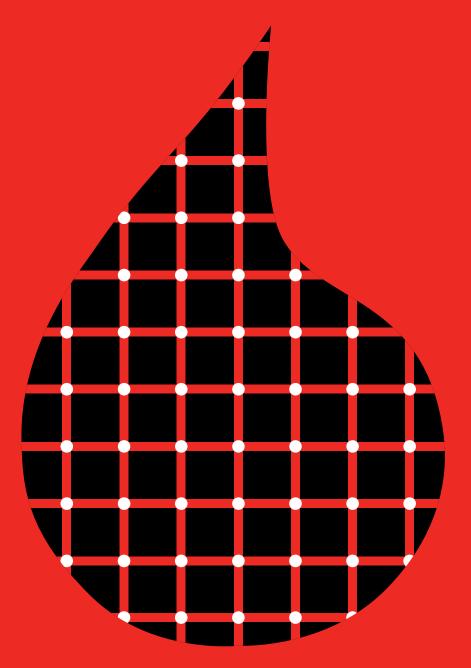
THEY SAY / BUT THEY SAY Hep B vaccination

PUTTING THE C IN COUNTRY Living with hep C in rural NSW



heptorgtahep.org.au / HEP REVIEW / 67

What can you see?



HEP C LIVES IN BLOOD

HEP C IS ONLY PASSED ON WHEN BLOOD FROM SOMEONE WHO HAS HEP C GETS INTO THE BLOODSTREAM OF ANOTHER PERSON.

Hep C can be passed on if you share injecting equipment including: NEEDLES, SYRINGES, SWABS, SPOONS, TOURNIQUETS, WATER, FILTERS, HANDS, or you share TATTOOING and PIERCING EQUIPMENT.

Aim to use only your own sterile injecting equipment and learn about safer tattooing/piercing.

HEPATITIS INFOLINE 1800 803 990





Hepatitis NSW Working towards a world free of viral hepatitis

