



# ADVOCACY FOR UNIVERSAL ACCESS TO HEP C MEDICINES

Helen Tyrrell  
Australasian Viral Hepatitis Conference 2016

# WHAT DO WE MEAN BY UNIVERSAL ACCESS?

- Who is eligible?
  - ✓ Medicare card
  - ✓ No PBS restrictions for adults
- What does it cost?
- Is there a treatment 'cap'?
- Who can prescribe?
  - ✓ Specialists
  - ✓ GPs
- Why is it important?
- This is the starting point for the goal of elimination



# REFLECTIONS - THE ADVOCACY JOURNEY

In the beginning .....

The consensus was that **the price was too high** to make the hep C medicines available to **everyone, everywhere**.

We were told we had '**rocks in our head**' if we thought we could get universal access - no other country had achieved this.

Many clinicians were pressing for priority access for segments of the population.



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# CHANGING THE NARRATIVE FROM PRICE TO VALUE

## WORLD HEPATITIS DAY JULY 2014

Presenting the facts  
and highlighting the need for  
immediate action to avert a liver  
disease crisis.



## PARLIAMENTARY MEETING SEPTEMBER 2014

Presenting the case  
to fund the new hepatitis C  
medicines to Parliamentarians.





**Speak Out** 

Speak out about the need to access a cure for hepatitis C



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# SOCIAL MEDIA CAMPAIGNS



# OPEN LETTER TO THE MINISTER – SEPTEMBER 2015



24 September 2015

The Hon. Susan Ley MP  
Minister for Health  
House of Representatives  
Parliament House  
Canberra ACT 2600

Dear Minister,

**Time for New Cures – Time to list new hepatitis C medicines**

It is rare that a government has the power to change the course of an epidemic but that is the historic opportunity available to you and your colleagues.

Australia is at a crossroads. Down one path lies escalating rates of liver disease and death. Down the other, there is an opportunity to make hepatitis C a rare condition in our lifetime.

The twenty-seven organisations which are signatories to this letter acknowledge your commitment to respond to the needs of healthcare consumers and reimburse new therapies that treat conditions ranging from cancer to eye disease. As such, we urge you to expedite price negotiations and confirm the addition of the new breakthrough hepatitis C medicines on the Pharmaceutical Benefits Scheme without delay.

These new treatments cure hepatitis C and represent a lifeline for many people. Yet despite being recommended by the Pharmaceutical Benefits Advisory Committee six months ago, these medicines are still awaiting consideration by the Federal Cabinet.

With exceptionally high cure rates, shorter treatment duration and fewer side-effects than existing therapies, interferon-free medicines hold the key to preventing liver cirrhosis, liver cancer and liver failure – not to mention halting the rising death toll associated with untreated hepatitis C.

As you know, treatment rates remain lamentably low. Only one per cent of the 230,500 Australians living with hepatitis C are treated each year. This puts thousands at risk of progressing to serious liver disease.

Of further concern are reports by liver clinic staff that hepatitis C treatment rates have plummeted again as more and more people find themselves in a treatment limbo.

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Sadly, Australia can no longer regard itself the "lucky country"; not when people with hepatitis C are being cured around the globe – from the United States and Great Britain to Egypt and India. Increasingly, desperate Australians are being forced to travel overseas, or take the risky course of importing medicines because these new therapies remain unaffordable in Australia.

Minister, it's time for action. It's time for you to intervene and bring the Department, the pharmaceutical companies and the Cabinet together to deliver the cures for which so many Australians are desperately waiting.

We implore you to embrace a new treatment era, to confirm a PBS listing date and make 2015 a watershed year in the fight against hepatitis C.

Yours faithfully,



Helen Tyrrell - CEO Hepatitis Australia

On behalf of the twenty-seven organisations listed below.

- Aboriginal Sobriety Group
- Anglicare – Tasmania
- Australian Federation of AIDS organisations.
- Australian Hepatology Association
- Australian Injecting & Illicit Drug Users League (AIVL)
- Australian Research Centre in Sex Health & Society
- Australasian Society for Infectious Diseases
- Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine
- Centre for Social Research in Health
- Gastroenterological Society of Australia
- Including the Australian Liver Association
- Haemophilia Foundation Australia
- Hepatitis Australia
- Hepatitis ACT
- Hepatitis NSW
- Hepatitis Queensland
- Hepatitis SA
- Hepatitis Victoria
- Hepatitis WA
- National Aboriginal Community Controlled Health Organisation
- National Association of People with HIV Australia.
- Northern Territory AIDS and Hepatitis Council
- Penington Institute
- Peter Doherty Institute for Infection and Immunity
- Shine SA
- Tasmanian Council on AIDS, Hepatitis and Related Diseases
- Uniting Care Wesley – Port Adelaide
- Uniting Communities

c.c. Senator the Hon Fiona Nash, Minister for Rural Health  
Senator the Hon Ken Wyatt, Assistant Minister for Health

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# MEDIA SNAPSHOT JULY TO DECEMBER 2015

- *Time for Action to prevent lives lost to viral hepatitis* - **July**
- *Recommendations alone will not avert a liver disease epidemic* - **August**
- *Tragic cost of delaying access to new cures revealed* - **September**
- *Government's proud record of subsidising medicines must apply to new hep C cures* - **September**
- *New medicines 'pay for themselves' but too many Aussies denied access – new analysis* – **November**
- *Innovation, Prime Minister, Yes Please!* - **December**

## OPINION EDITORIAL - 1 DECEMBER 2015

### **Innovation, Prime Minister? Yes Please!**

“Today should have been the day when Australia listed four of the most innovative medicines ever developed for the benefit of **Australians living with hepatitis C**. But despite PBAC recommendations that date back to March a timeframe for their listing remains entirely unknown.....”

“We have no doubt that the Prime Minister and Federal Health Minister believe in innovation and are committed to improving the health of Australians. The Prime Minister has met with one of his own constituents who is living with hepatitis C, so he understands the desperate need for access to a cure.....”

ANNOUNCEMENT - 20 DECEMBER 2015

**A One Billion Dollar Investment**  
in Hepatitis C Treatment over 5 Years!



Health Minister  
Hon. Sussan Ley MP



Prime Minister  
Hon. Malcolm Turnbull

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# TREATMENT ACCESS – SINCE 1 MARCH 2016

## OLD TREATMENT IN 2014

**2,790** people treated

**For the whole year**

## NEW TREATMENT IN 2016

Est **26,360** people initiated

on DAA treatment

**March to July 2016**

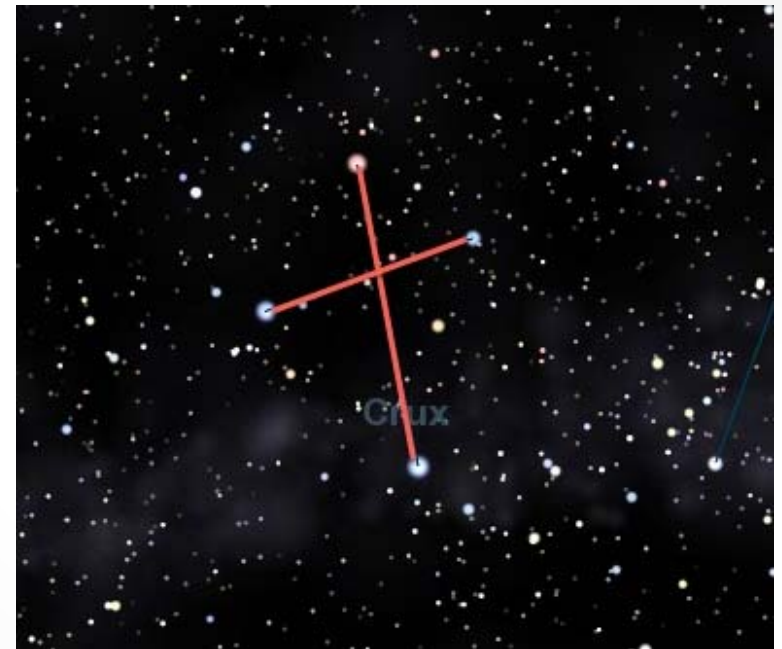
*"We have made a \$1 billion investment to fund revolutionary new treatments to cure Hepatitis C, which have been available on the PBS since the start of March. Australia is one of the first countries in the world to publicly subsidise these medicines for the nation's entire population of Hepatitis C sufferers, no matter what their condition or how they contracted it, with broad access through both specialists and primary care".*

Minister Ley 15 March 2016

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# ALIGNMENT OF THE STARS?

- Set your expectations high
- Convincing stats and facts
- Community voices
- Collaborations
- Media engagement
- Timing
- Politicians willing to listen and act



On the road to elimination

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# Questions?

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