



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.



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.



**TOGETHER WE CAN
SEE OUR
FUTURE**



STORIES OF COURAGE, RESILIENCE AND HOPE
FOR A FUTURE FREE FROM HEPATITIS C

Speak Out 

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



Speak Out 

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

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

SOCIAL MEDIA CAMPAIGNS

#TimeForAction

TO INCREASE
**HEPATITIS
TREATMENT
RATES**



TIME FOR NEW HEP C CURES

**It's a signature
moment, Minister!**



TIME FOR NEW HEP C CURES

**One signature ...
thousands of lives
changed forever**



Signature
Date

TIME FOR NEW HEP C CURES

**Sign now to make
hep C history**



TIME FOR NEW HEP C CURES



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

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

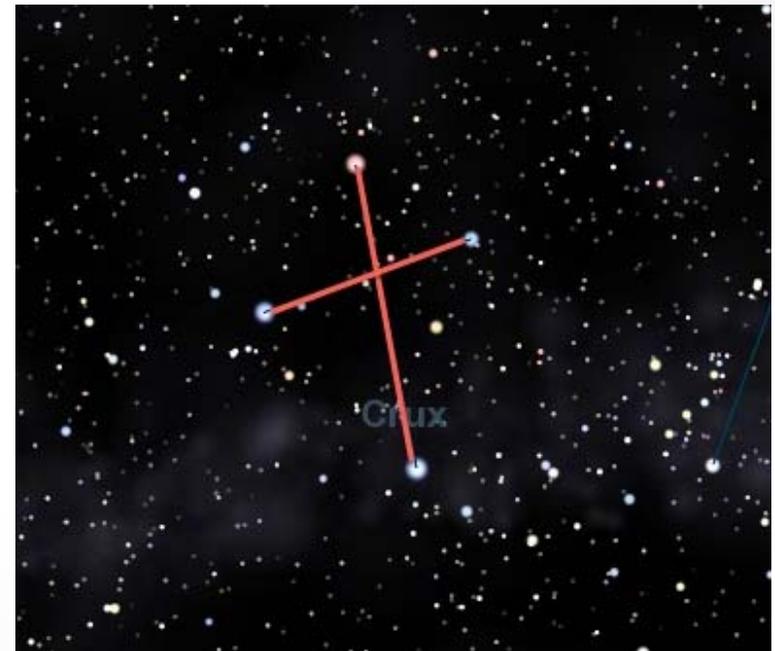
“We have made a \$1 billion investment to fund revolutionary new treatments to cure Hepatitis C, which have been available on the PBS since the start of March. Australia is one of the first countries in the world to publicly subsidise these medicines for the nation’s entire population of Hepatitis C 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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