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.

liver danger zone
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.
SOCIAL MEDIA CAMPAIGNS

#TimeForAction
TO INCREASE HEPATITIS TREATMENT RATES

It's a signature moment, Minister!
TIME FOR NEW HEP C CURES

One signature ... thousands of lives changed forever
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. Sussan 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-one organisations which are signatories to this letter acknowledge your commitment to respond to the needs of healthcare consumers and to remove 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 to the Pharmaceutical Benefits Scheme without delay.

These new treatments cure hepatitis C and represent a future 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 350,000 Australians living with hepatitis C are treated each year. This puts thousands of 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.

Sadly, Australia can no longer regard itself the “lucky country”, not when people with hepatitis C are being denied life-saving medicines.

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-one organisations listed below.

- Aboriginal Health Group
- Anglicare – Tasmania
- Australian Federation of AIDS organizations.
- Australian Hepatitis Association
- Australasian Society for the Study of AIDS (ASSA)
- Australian Research Centre in Sex Health and Society
- Australian Society for Infectious Diseases
- Australian Society for HIV, Viral Hepatitis and Sexual Health Medicine
- Centre for Social Research in Health
- Gastroenterological Society of Australia
- Greenshields Foundation (NSW)
- Hepatitis Australia
- Hepatitis ACT
- Hepatitis NSW
- Hepatitis Queensland
- Hepatitis SA
- Hepatitis Vic
- Hepatitis WA
- Health Promotion and Community Controlled Health Organization
- National Association of People with HIV Australia
- Northern Territory AIDS and Hepatitis Council
- Parliamentary Library
- Peter Doherty Institute for Infection and Immunity
- Queer Nation
- Tanspan Council on AIDS, Hepatitis and Related Diseases
- Uniting Communities - Port Adelaide
- Uniting Communities

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

hepatitis
australia
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**
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
“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
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
Questions?

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