UK Infected Blood Inquiry and Australia

The UK government Infected Blood Inquiry investigating contaminated blood and blood products released its report on 20 May 2024 after examining the evidence for 7 years. The UK government announced a financial compensation scheme to 'victims of infected blood' the following day. You can read the report at https://www.infectedbloodinquiry.org.uk/reports/inquiry-report.

Some of our community members have been asking what this means for Australia.

THE AUSTRALIAN SITUATION

In Australia the initial situation with collecting blood donations and testing the blood supply was different to the UK. Australia was one of the first countries in the world to introduce hep C testing of the blood supply and had a policy of self-sufficiency in the blood supply (ie, sourcing donations from Australia only). There was an Australian Senate Inquiry into **Hepatitis C and the Blood Supply** in 2004, which investigated and reported on the Australian situation and an Australian government **Inquiry into Hepatitis C in Australia** in 2015.

WHAT HAS HFA BEEN DOING?

In 2006-9 HFA undertook a hepatitis C needs assessment and described the burden of hepatitis C on our community members in our **Double Whammy** (2007) and **Getting it Right** (2009) reports. The HFA 2020 **Getting Older needs assessment** found that, although the greater majority of surviving people with bleeding disorders who had acquired hepatitis C have now been cured, many have ongoing health, financial and support issues. HFA has a committee working on a hepatitis C strategy to address this, including the approach to HFA's advocacy, which has been ongoing for more than 20 years now.

Eliminating hep C

In the HFA *Double Whammy* report people with bleeding disorders and hep C underlined that their highest priority was a cure. When the new treatments became available in Australia in 2016, we focussed on reaching as many affected people as possible to promote access to treatment and a cure. We are grateful to the HTCs for their tireless efforts to review their patients and encourage them to have hep C treatment and be cured.

Financial schemes

Although the 2004 Senate Inquiry into Hepatitis C and the Blood Supply recommended case management and financial support for health and community care costs of those who acquired hepatitis C through the blood supply, a formal program was never implemented.

Australian governments contributed to Hepatitis C Virus (HCV) litigation settlement schemes for eligible people who contracted HCV via the blood supply in Australia between 1985 and 1991, prior to the introduction of reliable screening tests for hepatitis C virus. However, eligibility for the scheme involved being able to link the individual's source of infection to a single donor with hepatitis C. HFA believes that nearly all people with bleeding disorders were excluded from eligibility as they had many treatments during this period and usually with clotting factor concentrates manufactured from the pooled plasma from thousands of donations and they could not identify a particular treatment batch or a single donor. Apart from a small ex-gratia payment that was made by the ACT government to people with bleeding disorders who acquired hepatitis C through the blood supply, there have been no other government financial recompense schemes for people with bleeding disorders in Australia.

HFA has been active over many years in hep C advocacy. Some key activities are below.

For a full list of HFA activities and links to the documents, visit the HFA hepatitis C strategy page on our website – https://tinyurl.com/hfa-hepc-strategy.

Overview of key HFA activities

2019-ongoing	HFA consultation with the bleeding disorders community and expert health professionals about ongoing issues with hepatitis C – see HFA *Getting Older with a bleeding disorder report* (2020). HFA is now working through a strategy to implement the report recommendations (government acknowledgement; health, financial and support issues).
2016-ongoing	HFA campaign to eliminate hep C in the bleeding disorders community and to promote liver health monitoring for those with cirrhosis. Includes: • work with Haemophilia Treatment Centres, hepatitis specialists and the community to overcome barriers to treatment and monitoring • education for the community and to GPs to reach those with mild bleeding disorders and those who are disconnected from HTCs.
2014-16	Community consultation on hep C treatment. Submissions to the Australian Government/ PBAC on access to new DAA hep C treatments
2015	HFA witness statements and submission to Australian Government **Inquiry into Hepatitis C in Australia**.
2010-ongoing	Further community consultation about financial issues. Meetings and correspondence with Australian governments on no-fault financial assistance scheme for people with bleeding disorders and hepatitis C and issues relating to out-of-pocket health care costs.
2006-2009	Needs assessment of people with bleeding disorders and hepatitis C and evaluation: **Double Whammy** and **Getting it Right** reports
2004	HFA Submission to Senate **Inquiry into Hepatitis C and the Blood Supply**, including a proposal for financial recompense
2003-4	HFA national campaign for universal access to recombinant clotting factor treatments (synthetic and virus-free)

The HFA Getting Older report highlighted that hepatitis C leaves an ongoing legacy for many in our community. We continue to work on a strategy to implement the report recommendations and will advise of any further steps and outcomes.

We are aware that revisiting these issues can be painful for some members of our community. We encourage you to reach out for support if this experience is challenging for you – eg, to your HTC social worker/psychologist or your preferred counsellor. You may also wish to seek a counsellor through your GP or contact a service like Lifeline (call 13 11 14).