

Introduction

In 2014 Hepatitis Victoria commenced training and supporting community advocates to speak about issues affecting people living with viral hepatitis. Since then advocates have raised public awareness, educated professionals, influenced organisations, and lobbied politicians.

Advocates seek to influence the public through a range of media including radio, TV, newspapers and social media.

They also seek to influence the political process through meeting Members of Parliament (State and Federal), participating in government working groups, and addressing forums where community decision-makers are present.



In 2014 Hepatitis Victoria set up a Community Advocates program, expanding the role of volunteers to include media work and other forms of advocacy.

We continued with our educational work and expanded our activities to increase public awareness of viral hepatitis. I was interviewed by local papers, on ABC radio and on Channel Ten.

In 2014 Community Advocates lobbied state politicians concerning the extent of viral hepatitis infection within their electorates and to gain support for a state hepatitis strategy. We also took part in public forums attended by state politicians and these efforts continued through 2015. In 2016 the Victorian government announced separate strategies for hepatitis B and C.

The new anti-virals changed the landscape. The Australian Government instituted an inquiry into Hepatitis C and several Community Advocates gave testimony at the Melbourne hearings in January 2015. Our lobbying efforts increased, aiming to have the new treatments listed on the PBS. In March the PBAC recommended their listing. In June I addressed a meeting of the Parliamentary Interest Group on Blood-borne Diseases where speakers reinforced the message. The efforts of many people and organisations came to fruition when the Minister announced the listing of new treatments in December, to become available in March 2016.

We now work to increase public awareness of the availability of treatments and to push for easier access to testing and treatment.

Working Group for the establishment of the first ever Victorian Hepatitis B Strategy. Furthermore, in 2016 the Victorian government announced separate strategies for Hepatitis B and C.

I have spoken at Hepatitis Victoria's *Western Action Forum* to address key decision makers including Members of Parliament to advocate for better Hepatitis B coordinated strategies. Also, I was recently invited to speak at the *2016 National Hepatitis Health Promotion Conference* in Melbourne.

Being a Community Advocate gives me the opportunities to raise awareness about hepatitis B to multiple audiences. It is also a platform to educate people about hepatitis B, to speak out against and dismantle stigma, discrimination and to let people know they can live a relatively normal life with hepatitis B.

Community Advocacy is challenging work, as it requires one to speak publicly about something so personal. However, I do this in the hope that people who are affected by hepatitis B have a better experience, access to care and management to prevent others from being in this position. As hepatitis B is something that can be prevented and managed.



Nafisa Yussf

I found out I had hepatitis B nine years ago and due to the lack of awareness and support for people affected by hepatitis B, I decided to join Hepatitis Victoria in 2013. Since becoming a Community Advocate, I have spoken at many platforms to communities, health professionals and policy makers to raise awareness and advocate for people with hepatitis B. In particular I was part of the Victorian Department of Health's Hepatitis B

Conclusion

Advocates believe their personal knowledge of viral hepatitis and its psychological, geographic and cultural aspects, has been critical to others' understanding, and its reflection in government policy making.

Being able to articulately share their personal experiences with a range of audiences has given advocates a sense of personal power, counteracting the negative experience of living with a serious chronic illness.



Ross Williams

I contracted hepatitis C in 1975 and was diagnosed in 1996. I had three unsuccessful interferon-based treatments over the next decade, and in that time I developed cirrhosis. My liver failed and I was transplanted in 2008. The virus persisted and cirrhosis rapidly developed. In 2010 I was again listed for transplant, and received a new liver in June 2012. The virus still persisted and by 2013 my liver was severely damaged. I undertook a treatment combining interferon with boceprevir. This finally cleared me of hepatitis C.

A few months into my final treatment, I became a volunteer at Hepatitis Victoria. I began by stuffing envelopes, and soon became involved in public speaking, talking of my experiences to health workers.

