



HIV/AIDS Legal Centre Incorporated (NSW) ABN 39 045 530 926

11 February 2015

Pharmaceutical Benefits Advisory Committee
PBAC Secretariat

via fax: 6289 4175

Dear Committee Members,

Submission to the Pharmaceutical Benefits Advisory Committee

Consideration of hepatitis C treatments at the March 2015 meeting.

1. LEDIPASVIR with SOFOSBUVIR

Section 100 (Highly Specialised Drugs Program) listing for the treatment of genotype 1 chronic hepatitis C virus infection in adult patients.

2. RIBAVIRIN

Section 100 (Highly Specialised Drugs Program) listing for the treatment of chronic hepatitis C viral infection (genotype 2 or 3) in combination with sofosbuvir in patients 18 years or older who have compensated liver disease.

3. SOFOSBUVIR

Section 100 (Highly Specialised Drugs Program) listing for the treatment of hepatitis C viral infection.

The HIV/AIDS Legal Centre is the only community legal centre in Australia specialising in legal issues arising from HIV and viral hepatitis.

We write in support of Pharmaceutical Benefits Scheme listing of these treatments for chronic hepatitis C.

HALC supports the application for these life-saving treatments to be listed for subsidy under the PBS, as soon as possible and to be available to all relevant patients without limitation.

Short and effective treatment enhances the ability of people with Hepatitis C to maintain employment during treatment and afterwards.

In our work, we find that our clients with hepatitis C most commonly face issues arising from

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their treatment, rather than their underlying condition. In particular, once they make the decision to commence treatment, they often face significant problems at work due to the very lengthy duration of current treatment and its often debilitating side effects. Clients have abandoned treatment because their only alternative was to lose their employment if they continued. Other clients have been forced to disclose the nature of their illness, and have then faced discrimination and harassment, even at workplaces where they have been employed for many years.

We recently represented Alf* in an anti-discrimination matter arising from his hepatitis C treatment with interferon and ribavirin. He described what happened at his workplace:

“When I commenced treatment for hepatitis C I decided to confide in my supervisor so I would have some support at work if needed. I believed that, as a valued employee of approximately 25 years’ service, I would be given support, if needed, from my employer. However, once my employer heard that I was on hep C treatment, I was instructed to stay at home. Once my sick leave ran out, I received no pay at all. All my employer could suggest was that I approach Centrelink for support. Since I still had a job, I was not eligible for unemployment benefits; and since I was not actually sick, I was not eligible for sickness benefit either. I contacted the HALC office to seek assistance as my limited savings were fast running out and I had no income. I felt stigmatised and discriminated against, and told HALC that I felt that I had somehow done something wrong.”

The significantly shorter treatment times offered by Sofosbuvir based treatments, along with the significantly reduced side effects, have the potential to prevent hepatitis C sufferers like Alf from having to disclose their condition and/or treatment plans to employers and others, sparing them the risk of discrimination and the associated distress. Additionally, workers with physically or mentally demanding jobs will be more likely to be able to complete treatment whilst maintaining their employment.

Treatment that enables employment and other aspects of normal life to continue will increase the number of patients both commencing and completing treatment.

Shorter and less debilitating treatments will result in an increased number of employed people, as well people with family and other commitments, reconsidering their current decision not to undergo treatment due to concerns that it would affect their ability to meet their obligations. Each such person successfully treated is a person who will not progress to more serious liver damage, and a person who will continue in their employment and other contributions to society. This is a real gain to the community.

Inclusion of new hepatitis C treatments such as these Sofusbuvir based treatments on the PBS will increase the uptake of treatment and thus potentially prevent many people from progressing to more serious liver damage such as cirrhosis and end stage liver disease. This, in turn, will greatly reduce the demand for liver transplant; and will reduce the 530 deaths estimated to be occurring annually in Australia from hepatitis C related liver disease.

Considering the present low rate of participation in hepatitis C treatment, there is a great need to provide access to new treatments which reduce or eliminate the need for interferon, the side effects of which dissuade many people from seeking treatment for hepatitis. The availability of less daunting treatments, which would encourage more people to seek treatment, has great potential to benefit not only individuals living with hepatitis C, but also the community at large by stemming the spread of the virus and reducing the cost of ongoing care for affected individuals.

Yours sincerely,

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