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**PBAC Secretariat – MDP 952**

**Department of Health and Ageing,**

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To Whom it May Concern,

**Re: July 2014 PBAC meeting Pharmaceutical Benefits Advisory Committee (PBAC)- Consideration of Hepatitis treatments Sofosbuvir and Simeprevir.**

The Health Care Consumers' Association (HCCA) of the ACT was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making. Hepatitis ACT is a member of HCCA and we have sought advice from them in framing this response.

HCCA supports the addition of Sofosbuvir and Simeprevir to the Australian Government's Pharmaceutical Benefits Scheme (PBS). HCCA strongly advocates for the introduction of these treatments in Australia to ensure choice, opportunity and access to these medicines which present significant advantages over currently available treatment options.

Please find attached the patient experience wheel of a 42 year old woman who has had chronic Hepatitis C for 20 years. This wheel contains quotes chosen by the consumer that reflects their experience with seeking current available treatment for Hepatitis C, her experience in supporting others through this and what the availability of Sofosbuvir and Simeprevir would mean to her quality of life. Quotes from her interview transcript are also included throughout this submission.

*"[when discussing her partner's treatment with Interferon and Riboviron] we basically flipped a coin and decided he would do treatment first. And it was horrendous and it was awful. By then they had gotten rid of the requirements that you talk to a psychologist and they...it was quite clear to me that they*

*were glossing over the possible side effects with patients, potential side effects for patients. They were just giving people huge amounts of pain killers and antidepressants and expecting them to be alright and a lot of them weren't alright. It wasn't just my partner at the time I had a lot of friends who were doing it as well, and they fell in to really deep serious depressions, and they were having really debilitating side effects. There are people who I know who have permanent physical side effects from damage from during the Hep C treatment– Consumer Story of seeking Hepatitis Treatment*

There is an estimated 230,000 people in Australia living with chronic Hepatitis C. In the ACT that number is approximately 4,000. Nationally less than 2% of the affected population is treated annually. That figure is lower in the ACT. The reasons for the very low treatment rates include the relative effectiveness, duration and toxicity of current treatments when compared with the promise of future treatments.

*And um I think one of the things was, a friend was saying she had no idea just how tired she was until she had treatment and cleared the virus and it changed her quality of life. So that kind of inspired me to go and look into it...AGAIN... On the basis that there were new drugs available or that they would be available. – Consumer Story of seeking Hepatitis Treatment*

Making these treatments available in Australia is firmly positioned in the Australian Charter of Health Care Rights particularly in regards to the charter right of Access and Safety. These treatments will provide considerably more access to a safer treatment. The ACT community will benefit from these new treatments as they create opportunities for more people to undergo treatment each year. They will increase in treatment rates by accelerating through-put of specialist clinics and by increasing demand for treatment, due to less ill-effects from treatment.

*But my thing is that I'm tired all the time and I always have been...Anyway in the last couple of years there have been new drugs that have been trialled for Hep C treatment and I have friends in other cities who have been on the trials, and some drugs make the treatment shorter and some drugs make the*

*treatment far more likely to work. - Consumer Story of seeking Hepatitis Treatment*

As seen in Hepatitis ACT's submission, Sofosbuvir and Simeprevir:

- present fewer side-effects than current treatments (especially for those people who can be treated without interferon). The reduction in side-effects will mean more people are able to work throughout their treatment course, while reducing the burden which many people feel they put on family members and friends.
- require shorter treatment durations (down from as many as 48 weeks to as few as 12 weeks for the majority).
- produce much higher cure rates (of more than 90% for most people).
- create an opportunity to reduce and prevent the 25 or more deaths each year in the Canberra region due to liver failure and liver cancer

Access to Sofosbuvir and Simeprevir will improve the health and wellbeing of affected communities and the ACT community more broadly. Affected individuals will experience better treatment access and cure rates and therefore better long-term health (including reductions in rates of cirrhosis, liver failure, liver transplant, liver cancer, and early death). Unrestricted access to these treatments creates an opportunity to reduce the burden of liver disease in Australia and has the potential to lower the rate of new infections by reducing the size of the affected population.

*“ [Consumer and Doctor] we were talking about the new drugs and he was saying they haven't been approved yet. He was saying cost, that they are expensive, that treatment is expensive. And I just said well surely....there is a rising in the number of people with Hep C, and that is expected to rise and so surely the health costs associated with that group of people who are going to get liver cancer or cirrhosis ...doesn't that justify treatment? And he was kind of saying...well maybe not on the governments cost benefit analysis. He was kind of saying, really the treatment should be provided to the people who aren't really sick yet, that's how you save money in the health system, but that is not how the government do it or things go on the PBS or whatever for subsidizing of the treatment. Which depressed me quite a lot I have to say*

*because the incidence of Hep C is increasing, and they reckon there is quite a lot of people who have it and just don't know they have it.*

*But because its not guaranteed to kill you, I guess its less of a priority...It just might...kill me.” –Consumer Story of seeking Hepatitis Treatment*

The current experience of treatment for Hepatitis is often a negative one. With debilitating side effects, Sofosbuvir and Simeprevir offer new hope for those living with chronic and acute Hepatitis in the ACT and Australia, both due to less horrific side effects in treatment and a stronger likelihood of clearing the virus therefore curing the person of disease .

HCCA strongly supports the position of Hepatitis ACT and advocates for the addition of Sofosbuvir and Simeprevir to the PBS.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Darlene Cox', is centered on the page.

Darlene Cox  
Executive Director  
Health Care Consumers' Association

10 June 2014