HOUSE OF REPRESENTATIVES

STANDING COMMITTEE ON HEALTH

HEPATITIS C INQUIRY 2015

SUBMISSION BY;

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VICTORIA

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INTRODUCTION

The writer is a 57 year old with chronic Hepatitis C. I have known of my positive HCV status since early 1991 when it was detected in the process of a routine health check. It is suspected that I contracted HCV in the process of childhood immunisation while living in Spain.

Following unsuccessful treatment with Alpha Interferon during 1996, which I was not able to tolerate, my health status rapidly deteriorated to cirrhosis and liver failure. Consequently in early 2000 I needed a liver transplant, following which I recovered good health with the significant support of medical aftercare and ongoing immune suppressants and other drugs. HCV has since continued to attack my new liver to the point of level 3-4 fibrosis, with an ongoing risk of my new liver becoming cirrhotic and my requiring a second liver transplant, and the always present risk of developing life-threatening liver cancer.

While the liver transplant effectively saved my life, chronic HCV and the transplant process has had an incalculable impact on my life over the last 20 years. It has negatively affected me personally, as well as those close to me. It has arguably reduced my work capacity and my overall ability to contribute to my community to my full capacity and desire. In pure financial terms, my condition and the ensuing treatments required has come at a high cost to myself, the tax payer and health system.

Late in 2014 I commenced treatment with two of the newly available direct acting antiviral drugs (Sofusbuvir and Daclatasvir) as part of a compassionate program supported by Gilead Sciences and BMS, the makers of the two drugs. The effectiveness of this treatment and my capacity to tolerate it with minimal, if any, impact on my daily life while on treatment, has astounded me and given me great hope.

While I am yet sometime away from being able to declare that I am cured from HCV, and that I may avoid ongoing related serious consequences like liver cancer, it is inconceivable to me that there can be any rational argument to withhold this type of effective treatment from any existing sufferers of HCV. To deny ready access to the now available treatments would in my mind be a seriously negligent and discriminatory act on the part the Australian Government and its agencies. In addition, withholding access to these treatments will contribute to the ongoing unchecked spread of HCV in our community with a heavy burden of disease on individuals and the community, with inevitable spiralling financial costs.

Approval of access to the now available drug treatments is now urgently required and it is the essential and irreplaceable first step in combating and eradicating HCV in Australia.

Terms Of Reference; Response

a. Prevalence rates of hepatitis C in Australia

The consensus estimate by a variety of Australian agencies and experts is that there are in excess of 230,000 Australians currently with HCV. This represents a public health challenge with almost unprecedented health system and economic implications.

In Victoria alone, the number of notifications under the Act in the years 2010-2013 exceeds 9000 individuals, with around 43 actual new notifications per 100,000 population per year. At that rate it cannot be said that that HCV is, or can be contained, to one sector in our community. The disease is endemic and its spread is not just related to *unwise lifestyle choices*.

Within the current strategic and clinical approach its spread is aided and abetted by the almost total absence of awareness and prevention activities, the absence of readily accessible early detection and testing, and ultimately the absence of effective and generally tolerable treatment. Arresting the growth in new infections, together with common comorbidities such as the need for liver transplantation and liver cancer, is reliant on immediate simultaneous action on all three areas.

HCV is already the leading cause of liver cirrhosis leading to liver transplantation and this is expected to grow exponentially in the next 20 years. Liver cancer is already the fastest growing cause of cancer deaths in Australia, with more liver cancer in Australia being attributable to HCV and HBV then any other cause. The number of hepatocellular carcinoma cases recorded in Victoria 2010-2013 is almost 3300, or almost 5 per 100,000 population.

The financial and health system cost of responding to HCV related liver failure and liver cancer (including the system's capacity to effectively respond to other health issues) through currently approved technologies and treatments will in the longer term far exceed the cost of an early intervention, prevention and treatment of HCV with newly available treatments. The cost of uncountable preventable early deaths is of course immeasurable, both in human and financial terms.

Most importantly, in 2015 it is in our hands and within our means to largely prevent it and change the costly course of HCV.

b. Hepatitis C early testing and treatment options available through: i. primary care. ii. acute care. iii. Aboriginal Medical Services. and iv. prisons.

It is estimated that only about 20% of people with HCV in Australia are aware of it. This is a major barrier to combating the disease and it must be urgently addressed and overcome.

The low rate of diagnosis in part related to the relative absence of early symptoms of the disease and the absence of an early detection strategy. Individuals who may suspect they have been exposed to HCV may also fear pursuing a diagnosis given the stigma that is associated with the disease, misinformation about 'absence of treatment', the actual or perceived extreme side effects of available treatments, and concerns about the need for invasive nature of procedures such as liver biopsy, which is no longer necessary in the detection or treatment of HCV.

There is an urgent need to devise and implement an early detection strategy across all settings. The strategy needs to correct factual misconceptions about HCV, provide information about relevant health management strategies and current and emerging treatment options, as well as direct individuals to a range of available support services.

Early and accessible testing models, as currently available in areas such as HIV in Australia and overseas, need to be explored and if appropriate adapted to HCV.

While ensuring that there is treatment capacity in the acute sector for the many for whom the newly available treatments may be too late and perhaps those with special medical needs, it is important that primary health settings including General Practitioners, be resourced and enabled to play an increasingly central role in detection and treatment of HCV.

c. The costs associated with treating the short term and long term impacts of Hepatitis C in the community.

Current estimates are that less than 1% of the affected community is receiving treatment. This is no doubt related, amongst other factors, to the low level of diagnosis and reluctance by many people with HCV to undergo the low tolerance (high side effect) treatments that are currently approved.

Much has been made of the high costs of the emerging direct acting antiviral drugs both in Australia and overseas, and that was central to the reasons provided by the PBSAC in rejecting the application by Gilead Sciences for approval of Sofosbuvir in July 2014. While there is no doubt a need to contain costs, the position to date reflects a lack of understanding of the actual costs to the community of not immediately providing the most effective treatment options. Comparable jurisdictions in north America and Europe, facing

no less costs or fewer economic challenges, have approved a range of the newly available drugs.

The long term costs of not providing the most effective and tolerable treatment seem to be seriously misunderstood or discounted, in favour of short term savings. HCV is a debilitating disease that eats away at individual's health (physical and mental), self-image and capacity for work and supportive personal relationships.

HCV is already the single largest precondition leading to liver transplantation. This medical technology has advanced significantly in the past 30 years, but it remains a high risk and very costly procedure which should be reserved for those where no alternative treatment is available. Even where transplantation may save the life of an individual and in that sense be declared successful, many such individuals will not recover to the point of being able to resume a normal working life, and they will in any case continue to require lifelong medical treatment, including further procedures, likely inpatient admissions and the use of expensive drug therapies. While there are strict preconditions to be met prior to being considered suitable for transplantation, many people die while on the transplant waiting list. Many more die prior to waiting list assessment or after being declared unsuitable for the waiting list.

HCV is currently the fastest growing cause of cancer deaths in Australia, with more liver cancer in Australia being attributable to HCV and HBV then any other cause and as a result is it projected that HCV related liver cancer in Australia will grow by 245% by 2030. This will be catastrophic for all the individuals involved, their families and communities, and for the already stressed health system that will be required to respond to this preventable epidemic. There are currently some 1500 lives lost to liver cancer in Australia annually, with the death to incident ratio being close to 1 to 1. This would not be allowed to go on with any other disease or activity, and it should not be allowed to go with viral hepatitis.

All the well-researched projections indicate that the short term cost of immediately approving available drug treatments will be far outweighed by the long term cost of doing nothing or delaying an effective treatment strategy.

Even without a vaccine, HCV is preventable in Australia today. With the right level of investment in newly available treatments and the right government action on a range of preventative and awareness raising approaches, the current HCV epidemic in Australia can be halted and HCV can be largely eliminated. Australians currently afflicted with HCV and the Australian community at large can be spared the burden and high financial cost through decisive action in 2015.

d. Methods to improve prevention of new Hepatitis C infections, and methods to reduce the stigma associated with a positive diagnosis through: i. the public health system. ii. Public health awareness and prevention campaigns to reduce morbidity caused by Hepatitis C. and iii. Non-government organisations through health awareness and prevention programmes.

There is an urgent need for an effective and readily available HCV vaccine and a range of public health agencies are currently working on its development. In the absence of that many Australian and international experts are nonetheless advancing the notion of treatment as prevention and the immediate application of that approach. If we can reduce the number of carriers of HCV, we will reduce the number of new transmissions.

Much of the stigma associated with HCV emerges from ignorance, the misunderstanding that it is primarily a disease of IV drug users, and the fallacy that it is highly contagious and there is no cure. These issues can and must be targeted through well developed and accurate awareness campaigns that will lead not only to prevention but broader understanding of the disease in the community. Naturally this must be underpinned by the approval of newly available treatments.

Awareness and prevention strategies must target and be tailored for specific communities, including those in the medical/health professions, prison staff, and those communities most at risk of acquiring HCV.

While it is essential that the public health system, including hospitals, community clinics and GPs are part of any strategy, it is also true that often NGOs are best placed to provide front line support services for those affected, including those with HCV and their families and carers. Most jurisdictions in Australia already have structures within the community (NGO) sector which can be built upon in support of broader strategies. This will however require some level of resourcing, at least in the short term.

HCV is preventable. If we can eliminate HCV from Australia, as many experts believe it is possible, we will eliminate the stigma associated with it and the burden of disease upon individuals and the broader community. Effective investment now will reduce the long term cost, it will save countless lives, and eventually free up resources that can be saved or applied to perhaps currently unknown treatments for other diseases.