Submission to the Senate Community Affairs References Committee Inquiry into Hepatitis C and Blood Supply in Australia

by the Australian Haemophilia Centre Directors' Organisation (AHCDO)

AHCDO is the peak medical body for haemophilia and related bleeding disorders in Australia and its membership consists of the medical directors of haemophilia treatment centers. AHCDO was incorporated in Victoria in 2000 however its membership had previously met for many years as the Medical Advisory Panel of Haemophilia Foundation Australia. AHCDO maintains the Australian Bleeding Disorder Registry (ABDR), a database established in part to track prevalence, treatment and outcomes of people with bleeding disorders.

Many patients in the care of AHCDO members have contracted hepatitis C and these infections may have resulted from the use of non heat treated plasma derived products for the management of their bleeding disorder. It is in this context that AHCDO now makes this submission addressing specific terms of reference.

The high infection rate of Hepatitis C for people suffering from haemophilia

- We note that this Inquiry's terms of reference asks for comment on the high infection rate of hepatitis C for people suffering from haemophilia, however it is pertinent that many people with other bleeding disorders, particularly von Willebrand Disease (vWD), for which plasma derived treatment products are the only ones available, have also been infected with hepatitis C.

- Data from the ABDR[1] suggests that 62% (n=206) of people with severe haemophilia A have hepatitis C; 64% (n=83) of people with moderate haemophilia A have hepatitis C and 40% (n=157) of people with mild haemophilia A have hepatitis C.

- Data from the ABDR suggests that 58% (n=28) of people with severe haemophilia B have hepatitis C; 42% (n=18) of people with moderate haemophilia B have hepatitis C and 40% (n=36) of people with mild haemophilia B have hepatitis C.

- Data from the ABDR suggests that 17% (n=64) of those people with vWD whose hepatitis C status has been recorded have hepatitis C. It should be noted that the ABDR data for vWD is incomplete and that more than half of the people registered on the database have not had their hepatitis C status documented.

[1] The ABDR does not collect data from NSW

The impact that blood-transfused Hepatitis C has had on its victims and their families

- AHCDO members believe that the impact of blood transfused hepatitis C on their patients and their families has been significant. It should be remembered that people with bleeding disorders often require life long on-going medical treatment as there are no cures. Those patients now infected with hepatitis C and their families must contend with another life threatening condition.

- Some of our patients will have come through the 1980s with a sense of relief that they had not been infected with blood transfused HIV only to face the risk of this different type of infection in the early 1990s. In fact those patients receiving plasma derived treatment products live with the constant threat of infection - in 2003 there were concerns about West Nile Fever and variant CJV disease being transmitted by blood. Of course, some of our patients are co-infected with both hepatitis C and HIV and carry a triple health burden.

- Data from the ABDR suggests that 15% (n=87) of people with a bleeding disorder and hepatitis C infection are also infected with HIV.

- Many of the people infected will have long term concerns regarding the development of cirrhosis and the need of a liver transplant, a procedure made more hazardous due to their bleeding disorder. Indeed, many of the patients of our members are already long term sufferers of hepatitis C.

What services can be provided or remedies made available to improve outcomes for people adversely affected by transfused Hepatitis C.

- People with haemophilia and other related bleeding disorders have their condition managed by one of 16 comprehensive Haemophilia Treatment Centres (HTC). These HTCs offer a range of professional services in addition to those provided by AHCDO members, including counseling -specifically for those infected by hepatitis C and HIV; advocacy and social work, and physiotherapy. The holistic approach to the welfare of patients taken at the HTCs is greatly beneficial and the federal government should be encouraged to ensure that adequate funding is available to ensure provision of al the services provided.

- AHCDO members are concerned about the treatment available for people who have been infected with hepatitis C and are also suffering from a bleeding disorder. Although AHCDOs policy on factor VIII and IX concentrates expresses a preference for recombinant products as the treatment of choice for all patients, many people, even those not infected with hepatitis C, are not able to access these preferred treatment products. Patients who have, for one reason or another, cleared the hepatitis C virus and are considered to be ‘virally free’ are often required, for lack of availability of recombinant products, to use plasma derived products to treat their bleeding disorders, thus subjecting themselves to the psychological distress of possibly acquiring another, as yet unknown,

blood borne infection. This distress could be alleviated by improving access to recombinant treatment products.

- Although there have been recent changes which allow easier access to antiviral agents to treat hepatitis C, AHCDO supports wider and easier access to these treatments.