About The Hepatitis C Trust

The Hepatitis C Trust is the national UK charity for hepatitis C. It is led and run by people with personal experience of hepatitis C and almost all of our Board, staff and volunteers either have hepatitis C or have had it and cleared it after treatment.

We are committed to raising public awareness about the virus; ending discrimination against people living with hepatitis C; creating an active community of patients willing to stand up and be heard, and providing information, support and representation for people with hepatitis C. In addition to providing direct services, such as a patient helpline and an outreach testing van, we also campaign across the UK for improved hepatitis C services, as well as better governmental responses to the virus.

Our vision is for hepatitis C to be eliminated as a serious public health concern by 2030.

The Hepatitis C Trust & the contaminated blood disaster

At The Hepatitis C Trust, we have worked closely with victims of the contaminated blood disaster since our establishment in 2001. Through our engagement with patients, and through our own experiences as patients, we have a significant understanding of the health impact of hepatitis C on the lives of victims and their families, as well as the wider financial and social impact felt by them as a result of their experiences.

A very significant proportion of the callers to our patient helpline, for example, are people that have contracted hepatitis C via a blood transfusion – with 363 calls in 2014 from people with a suspected route of transmission from blood products. In addition to providing support via our patient helpline, we also deliver health days to people who have been infected with hepatitis C via contaminated blood. These health days provide attendees with an improved understanding of how to self-manage hepatitis C, including advice on nutrition, exercise, stress and energy management, as well as information on new hepatitis C treatments.

Key concerns and recommendations

Financial support

As members of the Financial Review Group, we endorse the recommendations in the Group’s *Contaminated Blood: Financial Support: Conclusions and Recommendations*, and hope that the Scottish Government agrees to the full implementation of these recommendations in due course. While we endorse all of the Group’s recommendations, we would like to particularly highlight the recommendation contained within Proposal 5, that:
“The current thresholds for Stage 1 and Stage 2 of the Skipton Fund should be the subject of a specific, evidence-based review to create new criteria based on health impact, rather than focusing predominantly on liver damage.”

Hepatitis C is a virus that affects not only the liver but which has a much wider health impact, for example it can cause chronic fatigue; abdominal pains; joint pains, as well as mental health issues. Given this, it is essential that the extra-hepatic impact of hepatitis C not only on health also on a person’s ability to earn, to progress in a career and to build up adequate financial resources is recognised and reflected in any revised financial support system.

Implementation of the Penrose Inquiry’s recommendation

The Hepatitis C Trust welcomes the key recommendation of the Penrose Inquiry, that “the Scottish Government takes all reasonable steps to offer an HCV test to everyone in Scotland who had a blood transfusion before September 1991 and who has not been tested for HCV”, and we are pleased to be members of the Penrose Short Life Working Group, established by the Scottish Government to consider the implementation of the Inquiry’s recommendation.

Estimates state that up to 200 people in Scotland who acquired hepatitis C through a blood transfusion pre-1991 are still undiagnosed. It is entirely possible that these people may have inadvertently passed the virus on; meaning that the true number of people infected with hepatitis C via contaminated blood (either directly or indirectly) may be significantly higher.

Given that the numbers are not very large, what are ‘reasonable steps’ from a moral perspective may be hard to justify in terms of cost-effectiveness. There is, however, another group who were infected at the same time but remain largely undiagnosed and, because of the length of their infection, at very high risk of end-stage liver disease – those who experimented with drug use, perhaps injecting just once or twice, in the 1960s, 1970s and 1980s. The Hepatitis C Trust believes that efforts to offer testing to those who had a blood transfusion in that period could be widened to find this group for very little extra cost but with a much increased yield and hence improved cost-effectiveness. With 45% of the 36,000 people in Scotland with hepatitis C still undiagnosed, this is an opportunity that we must seize.

Hepatitis C treatment

Key to ensuring that the victims of the contaminated blood disaster receive justice for their experiences is ensuring that they are able to access hepatitis C treatment, along with people who contracted hepatitis C via other routes. With new hepatitis C treatments now available in Scotland which have minimal side-effects, greatly reduced treatment durations, and cure rates of upwards of 95%, it is essential that all people with hepatitis C have access to these treatments.

2 Schaefer, Martin et al., Hepatitis C Infection, antiviral treatment and mental health: A European expert consensus statement
The Scottish Government’s Sexual Health and Blood Borne Virus Framework 2015-2020, published in September 2015, recommends that priority, in terms of the timing of treatment, should be given to:

- patients with F3/F4 hepatic fibrosis;
- and/or patients with severe extra-hepatic manifestations of hepatitis C;
- and/or patients with significant psycho-social morbidity as a consequence of hepatitis C.

While The Hepatitis C Trust recognises and accepts that prioritisation, in terms of access to new treatments, should always be driven by clinical need, we also strongly believe that all steps must be taken (both by the Scottish Government and by NHS boards) to ensure that access to these cost-effective treatments is as wide as possible, both for victims of the contaminated blood disaster and others.

Relatedly, we strongly believe that the Scottish Government’s current annual treatment targets (of 1500 people per year) should be reviewed to ensure that these targets continue to be as ambitious as possible, given potential savings that have been made as a result of negotiations in prices for the new treatments, as well as additional money which could be made available via rebates from the Pharmaceutical Price Regulation Scheme.

**The Hepatitis C Trust**

**Summary of recommendations**

1) The Hepatitis C Trust fully endorses each proposal contained within the Financial Review Group’s recent submission to the Scottish Government, and strongly encourage the Scottish Government to implement these proposals as quickly as possible.

2) The Hepatitis C Trust strongly encourages the Scottish Government, along with partners, to fully implement the sole recommendation of the Penrose Inquiry by ensuring that any individual who may have received a blood transfusion prior to September 1991 is offered a hepatitis C test. Further to this, we believe that the implementation of this recommendation presents us with an opportunity to widen hepatitis C testing more broadly, particularly to individuals who may not otherwise access hepatitis C testing.

3) The Hepatitis C Trust believes that access to hepatitis C treatments should be made as widely accessible as possible, and that the Scottish Government and NHS boards must take all steps necessary to ensure that victims of the contaminated blood disaster (as well as people who contracted hepatitis C via other routes) are able to access new hepatitis C treatments in a timely manner.