

Press release

## **The European Haemophilia Consortium releases film *Living with hepatitis C and haemophilia in Europe* for worldwide distribution**

(Brussels, Belgium – June 24, 2019) The European Haemophilia Consortium (EHC) today announced the release of the film *Living with hepatitis C and haemophilia in Europe* from director [Goran Kapetanović](#). In creating this film, the European Haemophilia Consortium **calls on European governments to provide access to hepatitis C virus (HCV) treatment with direct-acting antivirals (DAAs) to all patients with haemophilia who were contaminated through government-provided treatment.**

This initiative is part of EHC's commitment to the many patient populations of the bleeding disorders community and a response and recording of tragic events in the bleeding disorders community. From the EHC 2016 survey on 'Hepatitis C and bleeding disorders in Europe:'

- In the 1980s and 1990s thousands of people with bleeding disorders across the world were infected with HIV and hepatitis C virus through contaminated treatment products.
- The extent of the infection, as well as the needs of those living with HCV was never properly assessed and most patients were never properly compensated for this infection.
- It is estimated that some 15,000 people with bleeding disorders were infected with HCV in 30 countries in Europe.
- According to EUHASS, a European pharmacovigilance programme for rare bleeding disorders, liver disease and hepatocellular carcinoma is currently the primary cause of death within the haemophilia population.
- Direct-acting antivirals (DAAs) are medicines with a 95% success rate for curing HCV and are commercially available in most European countries.

In 2017, the Council of Europe published a resolution CM/Res(2017)43 on principles concerning haemophilia therapies, which recommends that "*Treatment for hepatitis C with direct-acting antiviral agents should be provided to all people with haemophilia on a high-priority basis.*"

Viral hepatitis C is an inflammatory disease of the liver. Typically, infections have a symptomless course during life and might take three to five decades to cause a significant liver impairment. However, effects are severe and dramatically impact quality of life. A scarred liver, called cirrhosis, is an organ that has been completely transformed following accumulation of scars and fibrous tissue and as a consequence, patients may have altered liver enzymes in the blood and issues in detoxication. Alarmingly, some of them may bleed in the guts because their scarred livers stop blood flow through the liver, making the venous vessels to inflate, and some of them may break and develop hemorrhage in the gut. In the end, some of them might develop primary liver cancer.

For these reasons, people affected with hepatitis C and rare bleeding disorders are at a higher risk of internal bleeds and this will result in higher use of costly replacement therapies, hospitalization and a sharp decrease in quality of life. As people with rare bleeding disorders were infected in two to three decades ago, this means that they are now at a much higher risk

of developing hepatocellular carcinoma, which could require invasive, dramatic and costly medical procedures such as liver transplant.

“Hepatitis C is the biggest cause of mortality for people with haemophilia in many European countries,” says EHC President Brian O’Mahony. “Governments provided the treatment, which caused the hepatitis C. They now have a moral obligation to right this wrong and prioritize access to hepatitis C treatment for people with haemophilia.”

The film is part of the EHConversations Series and continuation of work in partnership with director [Goran Kapetanović](#) ([My Aunt in Sarajevo](#) (2016), [Kiruna-Kigali](#) (2012) and [The War Game](#) (2017)). Kapetanović has directed and produced *Women and Bleeding Disorders: Untold Stories*, *Haemophilia Stories* and *Inhibitor Stories* with EHC. No external funding contributed to the making of this film.

For additional commentary or information, please contact:

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Download this release in its entirety in

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About the [EHC – European Haemophilia Consortium \(EHC\)](#)

EHC – The European Haemophilia Consortium (EHC) is an international non-profit organisation that represents 46 national patients’ organisations of people with rare bleeding disorders from 27 Member States of the European Union (EU) and most Member States of the Council of Europe.

The EHC represents approximately 90,000 people diagnosed with a rare bleeding condition such as **haemophilia**, **von Willebrand Disease (VWD)** and other rare **bleeding disorders** across Europe. However, it is estimated that many more live with an undiagnosed rare bleeding disorder.

The EHC draws on the knowledge of patients, healthcare professionals, the scientific community, the European institutions and the pharmaceutical industry to share expertise within Europe. The EHC also collaborates closely with other European patient organisations to ensure a strong collective voice for people with rare bleeding disorders.

[Read More about the European Haemophilia Consortium \(EHC\)](#)