



**THE  
HAEMOPHILIA  
SOCIETY**

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## **PRESS RELEASE**

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### **HAEMOPHILIA SOCIETY LAUNCHES CAMPAIGN AS HEPATITIS C DEATH TOLL MOUNTS**

Over 40 people with haemophilia have died as a result of infection with the hepatitis C virus through treatment with contaminated blood products, the Haemophilia Society claimed today.

The Chairman of the Haemophilia Society, the Reverend Prebendary Alan Tanner, was speaking at the official launch of the Society's campaign, held at St Bartholomew's Hospital, for fair treatment from the government for those infected with the virus.

"Over 3,000 people with haemophilia have been infected with this potentially life-threatening virus through treatment with clotting factor concentrates before 1986," he said.

The Hepatitis C virus (HCV) attacks the liver. Current medical opinion is that about 80% of people with haemophilia infected will develop chronic hepatitis C - with the possibility of long term liver problems. Between 10 - 20% of these will go on to develop cirrhosis, and of these an unknown number will go on to develop cancer of the liver. The progression to severe liver disease can take up to 30 years but many people with haemophilia have already been infected for up to 20 years.

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"People with haemophilia were infected with the hepatitis C virus through contaminated blood products," said Rev Tanner. "Many were not told that there was a risk of hepatitis when they were given the treatment. They were infected in exactly the same way as over 1,200 people with haemophilia contracted the HIV virus - through treatment with contaminated blood products. Yet while those infected with HIV receive financial help from the government those with HCV receive nothing."

The lives of those infected can be seriously affected - with recurring health difficulties that affect their work and families together with the uncertainty of not knowing if they will be one of the unfortunate ones who go on to develop cirrhosis and/or liver cancer.

"The government have said that they do not intend to provide financial help for people infected with hepatitis C. I would ask the government how many more should die before they decide that HCV is an immediate threat to people with haemophilia.

"There is a debate on hepatitis C in the House of Lords tomorrow, which shows that parliamentarians are taking the subject seriously. I would like the government to take it seriously as well and would make the plea for them to accept their moral responsibility and act swiftly and decisively to provide help for people with haemophilia infected with this dreadful disease."

Launching the campaign, the Rev Preb Alan Tanner said: "The Society is not seeking legal compensation through the courts with a view to allocating blame or liability. The Society believes there is a clear moral case for the government to provide immediate assistance for those people with haemophilia infected with the virus."

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The campaign objectives are:

- \* More equitable treatment in financial terms between those people with haemophilia infected with hepatitis C through contaminated blood products and those infected with HIV through contaminated blood products, specifically:
  - \* An across the board ex-gratia payment to all those infected with HCV through contaminated blood products.
  - \* Access to a hardship fund for those who become ill and the dependants of those who die.
  - \* As a matter of urgency, payments to those who are already ill and the dependants of those who have died.
- \* Adequate resources for haemophilia centres to enable them to provide the best possible treatment and care for people with haemophilia and hepatitis.
- \* Adequate resources for research into the prognosis and treatment of HCV.
- \* A public education programme that provides reassurance about the methods of transmission of hepatitis C and explains that ordinary social contact is not a means of transmission.

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Note to newsdesk

The Haemophilia Society Campaign will be launched at the Boyle Room, The Robin Brook Centre for Medical Education, St Bartholomew's Hospital, West Smithfield, London EC1A 7BE, on Tuesday 14 March 1995 at 3pm. Photographers/reporters are invited to attend.

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## BACKGROUND INFORMATION

Haemophilia is a genetically inherited bleeding disorder where one of the proteins in the blood that helps it to clot is entirely or partially absent. Treatment is by injection of the missing clotting factor, which then allows the blood to clot. Without treatment there can be prolonged and painful bleeds into the joints which can cause crippling long term joint damage. There is also the possibility of life threatening bleeds following trauma such as accidents or operations.

Clotting factor concentrates are usually administered by injection to "top up" the missing factor concentrates in the blood of people with haemophilia.

Clotting factor concentrates have been heat treated since 1986 to inactivate the HIV virus. This heat treatment coincidentally inactivated the hepatitis C virus.

A test for Hepatitis C was developed in 1991, and it was then discovered that virtually all those people with haemophilia treated with blood clotting factor concentrates before 1986 were infected.

41 people with haemophilia have died as a result of liver disease between the years 1988 and 1993.

1,237 people with haemophilia were infected with HIV through treatment with contaminated blood products and 596 have died.

The government made ex-gratia payments for people infected with the HIV virus through contaminated clotting factor concentrates. These took the form of an initial hardship fund of £10 million, followed by an additional £20,000 to all those people with haemophilia infected with HIV, then a final cash payment dependent on circumstances of between £20 and £60,000. The funds are administered by the Macfarlane Trust.