



## Television

# Unspeakable: the truth about HIV-tainted blood in Canada



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### Unspeakable

Directed by Gregory Smith, Robert C Cooper, Andy Mikita, and Sarah Wayne Callies

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Distributed by CBC and

SundanceTV

For more on the Royal Commission of Inquiry on the Blood System in Canada see

<http://publications.gc.ca/site/eng/9.698032/publication.html>

When the HIV/AIDS epidemic started in the early 1980s little was known about how it was transmitted. The disease was initially associated with minorities (ie, the gay community, Haitians, and injectable drug users), and generally stigmatised and downplayed in the medical community. Stigma, along with the scarcity of knowledge, permitted the accidental contamination of blood products. The risk of infection for people regularly treated with blood products rose sharply and the haemophiliac community suffered. Their condition, which affects the body's ability to clot and makes them more susceptible to bleeding and bruising, meant that taking blood products (to supply clotting factors) was their only option for survival. Unfortunately, for thousands of them, this treatment also led to an early death.

*Unspeakable* is a drama series based on the books *Bad Blood* (Vic Parsons) and *The Gift of Death* (Andre Picard), and created by Robert C Cooper. The series focuses on one of the largest health-related scandals in Canada—the contamination of blood products with HIV and hepatitis C virus—in the 1980s and the repercussions up to the present day. Although accurate numbers are challenging to obtain, at least 2000 people who received blood and blood products were infected with HIV between 1980 and 1985. Another 30 000 recipients of blood transfusions were infected with hepatitis C between 1980 and 1990. Around 8000 early deaths resulted from tainted blood contamination. In fact Cooper, who has haemophilia, was one of the people infected with hepatitis C from tainted blood during that timeperiod. The series follows the life of different families with members (including children) with haemophilia, as they struggle for information, policy implementation, and ultimately justice and compensation.

One family, the Sanders, are an inspiring example of how patients can, and should, be involved in healthy policy decision making—an issue that continues to be relevant. Will Sanders (Michael Shanks), whose son Ryan has haemophilia, worked for Public Health in Canada. Since the appearance of the first news about HIV, and the potential for spreading through blood products, he fought alongside his wife Margaret (Sarah Wayne Callies) for collecting evidence of disease transmission and for the right to inform the public. In the early 1980s, the Canadian medical system had insufficient blood donations to supply demand, which meant they were dependant on external donations, particularly from the USA, which included blood provided by prison inmates who were a high-risk group for infectious diseases. The shortage in blood supply and a fragmented decision-making system in Canada regarding blood products resulted in inefficient protective measures, including screening.

Crucially, the Canadian Red Cross dismissed reasonable evidence that HIV could be transmitted by blood, which seriously compromised the public health of the country. Blood products were not tested for HIV until 1985, after deaths from AIDS had already been reported from tainted-blood sources. To further contribute to the scandal, stocks of untested blood continued to be distributed as late as November, 1987, because of the high costs associated with fully replacing the blood products already purchased. People with haemophilia were already at a great risk of infection, particularly because in the early 1980s, patients were receiving blood-factor concentrates that had a mixed concentration of as many as 25 000 donations. Only one infected donation was needed to transmit the disease to the recipient. Yet again, patients were not advised against the risk associated with these concentrates.

Another key topic of *Unspeakable* is the stigma associated with HIV, which, unfortunately persists today. In the 1980s, the first HIV cases occurred mostly in gay men and injectable drugs-users and they were stigmatised for this reason. However, with the tainted-blood scandal unfolding, people with haemophilia also started being stigmatised. “I have a bracelet, which I often didn't wear because I didn't want people to know that I had haemophilia, because of the stigma and prejudice that was being levelled at people at that time”, said Robert Cooper in an interview for the *Vancouver Courier*. This lack of understanding and fear is illustrated in *Unspeakable* when Margaret is fired because of negative attitudes towards her son's condition, and eventually her own HIV status, or when they are chased out of a supermarket because people felt uncomfortable with Ryan touching the food.

A second important part of the TV show relates to the Krever inquiry, named after Justice Horace Krever and played by Matt Craven. It was a Royal Commission of Inquiry on the Blood System in Canada set up by the Privy Council and launched in 1993. This inquiry aimed to listen to the accounts of people affected by this scandal and their families, to determine who was responsible for the absence of action in the Canadian blood system, and to provide a framework to avoid a similar problem in the future.

This series is interesting—albeit tragic—not only for its historical account, but also for the subsequent lessons learned that are as relevant today as they were in the 1980s. The most compelling lesson is the importance of listening to those affected by decision making and that scientific evidence and informed policy decisions are always worth more than a price tag.

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