

# The Infected Blood Public Inquiry NEWSLETTER



THE  
HAEMOPHILIA  
SOCIETY

## *A summary of Inquiry hearings from London*

There have been many poignant photos shown at the Infected Blood Inquiry this week.

The pictures often featured young faces at the start of life, with big plans for the future.

Liz Hooper displayed two wedding photos during her evidence. Her first husband Jeremy, had haemophilia B and died aged 43. Her second husband Paul had haemophilia A and died two years ago at the age of 53. Yet Liz told the Inquiry she had been a “privileged” woman. She said: “I have my first love and my soulmate. They will always be with me and I will love both of them equally.”

Frankie described the start of her married life aged 18 to Mr AN, who had severe haemophilia. She said: “We had aspirations of being the best we could be. Everything that came afterwards totally destroyed that.” She told the Inquiry that her husband contracted HIV. She was advised by doctors to terminate two pregnancies because of the potential risk of passing on HIV. Those decisions, she said, still haunt her today. She then went on to contract HIV. Her marriage, once full of hope, collapsed.

Amanda Beesley described the heartbreak of the death of her hus-

band Andrew from HIV aged 32 in 1999. She said: “I could not believe that such a special person could love someone as ordinary as me.”

Others praised the courage and strength their partners had provided. Mr AM, who was infected with HIV aged four, said of his wife: “Many would have run the other way. You ran into my arms and I still ask myself why and I am forever grateful that you did.”

The power of love was tested beyond its limits by the contaminated blood scandal. Those who were able to hold on to it understand their good fortune.

## *Inquiry news*

Mark Ward, founder of the support service Haemosexual, and his husband Richard Dudley-Smith gave evidence on Thursday. Mark described growing up as the “school freak”, missing school through his haemophilia and bullied for being different. Diagnosed with HIV aged 14, Mark struggled with understanding where his haemophilia and HIV fitted with being gay. Unable to find people to talk to about it, he ultimately took on that role himself, helping to educate communities about haemophilia and HIV. Despite being told he had only weeks to live a number of times in his life, Mark pulled through and, in 2003, met his husband Richard. Mark said he had come to accept that “someone like him” would remain single. Richard described feeling “invisible” at Mark’s hospital appointments and was critical of the lack of mental health support available. Thank you both for your powerful evidence.

## Quotes of the week

“I have known and lost two of the best human beings ever to have walked this Earth. For me, it’s about answers. I want to know why.”

Liz Hooper, who was widowed twice as a result of contaminated blood

“I have never had any period of my life where there has not been any infection there. It’s tragic, but if I could get more emotional about it I would, but I am just burned out. I don’t have any left.”

Robert Hodgkins who contracted HIV and Hep B, C and D

“I turn to my country and I ask ‘why have you forsaken us?’ Politicians must engage now, but not just political figures—our Royal family and celebrities. Why has no one ever championed our cause?”

Mr AM who was diagnosed with HIV aged 4.

“Every time it gets told, it kills me a bit more and I don’t want to die anymore. I want to live.”

Frankie, describing her two abortions in the 1980s, carried out on the advice of doctors to avoid the risk of HIV

“Me speaking out meant others didn’t feel pressured, yet placed my family in the firing line. For me there was no choice. How could I think about representing our community from the shadows?”

Mark Ward, on his work to raise awareness of haemophilia in the gay community and beyond.