

# The Infected Blood Public Inquiry NEWSLETTER



THE  
HAEMOPHILIA  
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## *A summary of Inquiry hearings from Edinburgh*

This week the Infected Blood Inquiry has moved to Edinburgh.

Sir Brian Langstaff, chair of the Inquiry, acknowledged that Scottish victims of contaminated blood had already invested "time, effort and expectation" in a public inquiry and would be "forgiven" for not wanting to contribute to another.

The Penrose Inquiry's final report in 2015 was widely criticised as a "whitewash".

Sir Brian said his Inquiry would "draw its own conclusions".

The first witness was Alison Bennett, whose son Alistair, who had severe haemophilia A, died of HIV aged 22 in 1995. Alison told the Inquiry that she believed the reason HIV/

Aids was not on her son's death certificate was a "genuine attempt to obscure what happened".

John McDougall described his heartbreak at being told his seven year old son Euan had been infected with HIV.

Both he and Alison told the Inquiry that their marriages had collapsed under the strain of dealing with the deaths of their sons.

Alice Mackie, whose husband Robert has haemophilia and was infected with HIV and Hep C, described how stigma around the condition had led to a "life of loneliness". She outlined the huge scope of the research she's undertaken to back her belief that her husband was part of a cohort,

well known in medical circles, which was subjected to regular Aids testing without their knowledge.

Eileen Dyson, who at 29 thought she was on her way to a high flying career before she contracted Hepatitis C through a blood transfusion, challenged Sir Brian at the end of her testimony.

She asked him how "loss of potential" could be measured. Eileen said at the age of 29 First Minister Nicola Sturgeon was a junior solicitor and former Prime Minister John Major had not yet entered parliament. "I hope those examples focus minds", she said.

The Inquiry will sit in Edinburgh next week from July 8-11.

## Quotes of the week

"There is nobody out there that can treat a haemophiliac with all these viruses. We shouldn't have to fight for this. Somebody should be there to help us. They treat haemophiliacs not as people, but as experiments."

Alice Mackie, whose husband Robert was infected with HIV and Hep C through treatment for his haemophilia

"For those infected or affected who feel they can't give evidence or can't come here and give evidence, I salute you. Take care of yourself because for you that is the right thing. This isn't easy."

Ms S, whose mum contracted Hep C through treatment for VWD.

"Words are inadequate and fail to convey the whole truth. The enormity of my pain and suffering remains hidden and indescribable."

Eileen Dyson who was infected with Hep C after a blood transfusion

"We felt we'd conquered haemophilia." John McDougall on getting prophylactic treatment for his 4-year-old son, Euan in 1981. Four years later they were told he had HIV.

"At that point I realised something was seriously wrong. I had gone for 10 years never realising that my infection could have been avoided. "

Bill Wright, on discovering that there were alternative treatments to factor VIII available for his mild haemophilia in 1986

## *Inquiry news*

A witness at the Infected Blood Inquiry on Wednesday claimed that her interferon treatment had triggered a rare and extreme autoimmune condition which had turned her life upside down. Gill Fyffe, who contracted Hep C from a blood transfusion in 1988, finally rid herself of the virus only to develop Lupus SLE which has made her extremely photosensitive and has forced her to mainly "live in the dark". Although her doctors were sceptical about the link between Interferon and her Lupus, Sir Brian said he had read at least three or four other witness statements that claimed interferon had made their skin extremely photo sensitive. His intervention highlights why it is so important everyone's experiences are recorded. Only then can similarities such as this be picked up.