

The Infected Blood Public Inquiry NEWSLETTER



THE
HAEMOPHILIA
SOCIETY

A summary of Inquiry hearings from London

The final week of the first phase of the Infected Blood Inquiry has heard more courageous experiences of those infected and affected by the contaminated blood scandal.

An anonymous witness, Mr AR described his unique position of being a junior doctor with haemophilia in the 1970s. Despite his warnings to his superiors of the risks of transmitting hepatitis through blood products, he was infected with hepatitis C himself and felt his concerns were ignored.

Nicola Jones, who is a haemophilia carrier with low factor VIII levels,

described being infected with hep C aged nine. She and her parents were told by doctors her health problems were “all in her head”.

Alan Burgess and his daughter Sarah bravely described the huge physical and psychological toll his HIV and hep C infections had had on three generations of their family.

In his closing comments, Inquiry chair, Sir Brian Langstaff, thanked every witness for having the courage to expose their “personal pain” in order to help others.

Sir Brian said: “They have painted a composite picture which will

help in trying to establish the truth.” Referring to the financial dire straights which many witnesses find themselves in, Sir Brian urged the Government to address the disparities in infected blood support schemes across the home nations immediately. He said: “The grinding hardship of many is not put on hold as the Inquiry continues.”

Sir Brian said he would not be afraid to call out wrongdoing when the time came. He said: “If there is criticism to be made, I shall make it and I shall not hesitate to name names where it is appropriate.”

Inquiry news— what happens next?

The Inquiry has heard from 189 witnesses in public, but is also processing vast amounts of data behind the scenes. It has reviewed 11.5m documents, with 2.5m pages now on the Inquiry’s document system—a number which is growing by 40,000 a week. Sir Brian said his task felt like “solving a million-piece jigsaw”. From Feb 24, 2020 the Inquiry will hear from expert witnesses on haemophilia and other bleeding disorders, hepatitis C and HIV as well as the psychosocial impact of being infected or affected. In June the Inquiry will investigate “decision makers”. Sir Brian said this would be clinicians and other witnesses “who can shed lights on the policies and practices of centres from across the UK who were most closely involved at the time”. He said they would “tell us about what happened and why”. A date for the June hearings has not yet been set.

Quotes of the week

“Today after all these years, giving evidence is my emancipation, today is my coming out and I shouldn't be scared. My community has earned the right to be listened to.”

Stuart Gregg who spoke out publicly for the first time about his HIV and hep C infections.

“They are only starting their lives and I want them to be happy and it's breaking my heart to see them hurting so much. The pain they are suffering emotionally just now is far worse than any bleed they have ever had.”

A letter written in 1994 from the mum of witnesses Paul and Myles Hutchinson to their consultant. The brothers were infected with hep C.

“I recall my legs shaking. I recall feeling physically sick and weak. My immediate thought was 'that's what the guys are testing us for'.”

Violet Slater on reading about Aids for the first time. She and her husband Malcolm, who has haemophilia and was infected with hep C, were tested at home by researchers wearing blue “scene of crime” suits. They were never told why.

“I am 61 years old now and I was diagnosed when I was 27. This is not over. The pain and trauma has been ongoing for all these years, compounded by the government's response.”

Alan Burgess, who gave evidence with his daughter Sarah. Alan was told he was HIV positive by letter in 1985.