

The Infected Blood Public Inquiry NEWSLETTER

August 2019



THE
HAEMOPHILIA
SOCIETY

Infected Blood Inquiry – key themes start to emerge

As the Infected Blood Inquiry hearings take a break over the summer, many of us will be reflecting on what we've heard so far.

For those of us who have attended the hearings in Cardiff, Edinburgh, Leeds, Belfast or London or followed them online it has been a moving and often difficult experience, but it has also brought our community together and been a source of support and comfort.

The Inquiry has now heard from more than 120 people infected or affected by the contaminated blood scandal and expects to receive 3,000 written statements. Inquiry chair, Sir Brian Langstaff, continues to encourage anyone who has not yet given evidence to come forward and has promised to read each statement personally.

Although it is hard to generalise, it is clear from testimonies so far that there are many common experiences, such as:

- Lack of consent for testing for HIV and Hepatitis
- Long gaps between diagnosis and telling patient of diagnosis

- Huge psychological impact on those infected and affected
- 'Jumping through hoops' to get basic financial support
- Stigma around HIV and Hep C
- Lack of monitoring of people with Hep C
- Missing, incomplete and/or inaccurate medical records

Much of the evidence has involved terrible loss, which is as raw today as when it happened, often many decades ago. Survivors frequently refer to themselves as "lucky", simply because they are still alive, despite many years of chronic ill health and struggle.

Every witness has spoken with great courage and we thank everyone who has done so.

The Infected Blood Inquiry will resume on 8 October in London where there will be a further three weeks of hearings, followed by evidence from expert groups. The hearings will take place 8-11 Oct, 15-18 Oct and 29 Oct – 1 Nov.

'It gave us comfort to know we weren't alone'

Christina McLaughlin and her siblings, Patricia and John, gave evidence to the Infected Blood Inquiry in Belfast about their brother Seamus who had severe haemophilia and died of liver cancer last year aged 45.

Many people who had not felt able to speak out thanked her for her testimony. Christina said: "If we were going to open our lives up in that way then it had to benefit more people than just us, and I think it has."

The experience of meeting others at the Inquiry who had gone through similar loss, anger and frustration was a great support to the family,

Christina said. "We've always been very isolated here, but it was so lovely for Sir Brian to bring it to Belfast so that everybody could get there and get involved. It gave us a lot of comfort to know that we were not alone."



The contaminated blood scandal has had a big impact on Christina's family, including her son Luke, 16, who has severe haemophilia. Christina said: "It's important to remember the third generation – they're not infected but they're badly affected. Young people with haemophilia need reassurance that the Inquiry is there as a support to them as well."

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NEWS IN BRIEF

Inquiry: Expert evidence

In November the Inquiry will hear five days of evidence in London from members of its expert groups. They will look at the psychological and social impact of those infected and affected as well as provide evidence on current clinical knowledge of haemophilia and other bleeding disorders, HIV, and hepatitis.

Investigation team

Although the hearings have taken a break, the work of the Inquiry continues with a team of 130 people sifting through millions of documents and records. There is also a team based at the National Archives in Kew, where

they are reviewing government documents.

Giving evidence to the Inquiry

It is not too late to give evidence to the Inquiry. You can contact the Inquiry directly on [0808 169 1377](tel:08081691377).

If you would like any guidance, you can contact The Society's public inquiry team at publicinquiry@haemophilia.org.uk

Service of Remembrance

The Haemophilia Society's Service of Thanksgiving and Remembrance takes place on [Saturday, 26 October](#) at [2.30pm](#) at St Botolph without Bishopsgate, London EC2M 3TL.

The service is to remember those who have died from contaminated blood products within the bleeding disorders community.

Due to greater awareness of the service, the service will be ticketed so that we can ensure the wellbeing of each of our attendees.

To book your free place, please visit haemophilia.org.uk/events-page/service or contact us on [020 7939 0780](tel:02079390780) or at events@haemophilia.org.uk

If you are unable to attend but would like a candle lit or a name entered in the Book of Remembrance, please contact us.

Victims put at the centre of the Inquiry

Inquiry chair, Sir Brian Langstaff, has impressed many people with his approachable style and close attention to detail.

From the start Sir Brian promised to put the victims of the contaminated blood scandal at the heart of this Inquiry. He, along with his Inquiry team, chat to people attending the hearings during all the breaks and Sir Brian will usually make time to speak to each witness personally before or after they have given evidence.

Sir Brian, a retired High Court judge, will often give a reassuring word to witnesses. To the daughter who blamed herself for administering contaminated factor VIII to her father, he said: "You are no more guilty than the syringe itself".

Angharad Shurmer, principal associate of Eversheds Sutherland, The Haemophilia Society's legal representatives, who has worked on a number of public inquiries, said: "Many inquiries set up a base and witnesses and members of the public are expected to travel to it. However, this Inquiry's approach is different and is going to the witnesses.

She added: "As with all inquiries there is a real need for the evidence to be gathered, processed and made public as quickly as possible. Often inquiries will focus on documents in the first instance and then move on to hear the public evidence. However, it is clear that the chair, Sir Brian, wishes to hear evidence in the first instance and then focus on documentation before the next phase of public hearings."