

# The Infected Blood Public Inquiry NEWSLETTER



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## The Infected Blood Inquiry looks ahead to 2021

Clinicians from many of the UK's major haemophilia centres have given evidence to the Infected Blood Inquiry in the last three months.

With proceedings affected by Covid-19 restrictions, the inquiry was forced to put hearings on hold until September, when they were able to resume taking live evidence.

Although lockdown rules meant that some clinicians had to take part via videolink, the inquiry was able to continue and believes it is still on course to produce its final report in 2022. You can read an analysis of clinicians' evidence later in this newsletter.

Looking ahead to 2021, inquiry chair, Sir Brian Langstaff, said speed and thoroughness were important to him as he set out his timetable for the year to come. Clinicians will continue to give evidence in January and there will also be two days of evidence from the inquiry's medical ethics expert group.

In February, The Haemophilia Society will give evidence, followed by a three week look at Trusts and schemes. There will also be evidence about Treloar School.

After Easter, campaigners and government witnesses, including ministers and civil servants will be called to give evidence.



In the autumn pharmaceutical suppliers and blood services will be investigated.

Speaking at the end of this year's hearings, Sir Brian said:

*"The evidence of one clinician is not always easy to reconcile with that of another, or the documents, or the evidence of those infected and affected: like all of us, they are people, and have different ways of looking at what happened and different abilities to address it when recalling the past."*

*Overall, a broad picture of what happened, and why, is slowly beginning to emerge for me; and a foundation for concluding what might have been done is gradually being laid."*

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## An analysis of clinicians' evidence by Katie Gollop QC, counsel for The Haemophilia Society



The inquiry has now heard evidence from 16 doctors treating patients with haemophilia in the 1970s to 1990s. Important themes have been patient knowledge, choice and consent to treatment.

Several doctors have said that patients already knew all about hepatitis non A non B (NANB) and AIDS from newspapers, Society meetings and publications like the Bulletins. But when pressed to describe what information they provided about these emerging diseases, the pros and cons of cryoprecipitate, NHS and commercial Factor VIII concentrate, and precautions to take, most doctors have been unable to answer.

Last week, we saw the inquiry's barrister pushing back against their reliance on pre-existing patient knowledge. She has asked them to confirm, which they have, that it was their duty as doctors to give patients the information the patients needed to provide informed consent to treatment, not the patients' responsibility to educate and inform themselves.

A related theme, repeated by doctors almost without exception, is their belief that even when patients knew that imported Factor VIII

concentrate put them at risk of developing AIDS, and that AIDS could be fatal, a return to cryo was not something they would accept.

What does that that belief tell us? Arguably more about the haematologists' consensus view that cryo was an unreliable, bad treatment and their fear of putting patients at risk of a fatal cerebral bleed, than about the decision each individual patient/parent would have made. Did doctors assume that because in the past, haemophiliacs had tolerated hepatitis B infection and jaundice as a price worth paying for the benefits cryo brought, they would make the same trade off in relation concentrate and AIDS, plus or minus hepatitis NANB?

***“We will never know for sure what decision patients and parents would have made if they had been given balanced information about the risk of death from AIDS using concentrate, versus the risk of a fatal cerebral bleed using cryo.”***

We will never know for sure what decision patients and parents would have made if they had been given balanced information about the risk of death from AIDS using concentrate, versus the risk of a fatal cerebral bleed using cryo. But the inquiry has yet to hear from any parent or patient given a free and informed choice between the two.

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The inquiry has produced written presentations on several Centres including Cardiff, where the late Professor Bloom worked. Readers may recall that Professor Bloom was Chair of the Haemophilia Centre Directors' Organisation and the most senior member of The Society's Medical Advisory Panel before and during the AIDS crisis. His advice, published by The Society in May 1983, was that the cause of AIDS was "quite unknown and as AIDS had not been proven to result from an infection in blood products, people with haemophilia should carry on using Factor VIII concentrates.

The Cardiff presentation makes for shocking reading. It highlights the significant gap between the information about AIDS and haemophilia available to Professor Bloom (and other doctors) from 1982, and his strong recommendation to The Society and its members.

Emerging clearly is the stark disagreement between doctors about how they should use the growing body of information connecting AIDS, liver damage, haemophilia and Factor VIII concentrate when advising and treating patients and parents.

Some experts, such as Professors Bloom and Lee, required scientific proof before they were prepared to advise departure from treatment with untreated concentrates. Others favoured "the precautionary principle" – AIDS and hepatitis NANB were a public health emergency and in matters of

public health, action to minimise risk should not wait for proof.

We are still at an early stage in the inquiry's evidence and issues such as self-sufficiency, government action and the financial support Trusts will be explored next year. Please stay in touch and let us know your thoughts.

## **Inquiry timetable 2021**

### **Week of 11 January**

12 January - Dr David Bevan, St George's Hospital

13 January - Presentation on Manchester Haemophilia Centre

14 January - Dr Janet Shirley, haemophilia centre at Frimley Park, Surrey

### **Week of 18 January**

19 January - Prof Peter Collins, Cardiff Haemophilia Centre

### **Week of 25 January**

26 and 27 January - Medical ethics expert group

### **Weeks 1 February and 8 Feb**

The Haemophilia Society

### **Weeks 22 Feb, 1 March and 8 March**

Trusts and schemes

### **Week of 22 March**

Treloar's and smaller haemophilia centres

### **Week of 29 March**

Haemophilia treatment and care in Northern Ireland, evidence from Dr Gary Benson

### **April onwards**

Campaigners and government witnesses

### **Autumn 2021**

Pharmaceutical suppliers and blood services

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## NEWS IN BRIEF

### Ethics experts give their verdict

A panel of six experts will give their views on some of the ethical questions posed by evidence so far. The inquiry's Medical Ethics Expert Group, which is made up of legal, clinical and academic experts, will present its report in live evidence on 26-27 January.

The report looks at issues such as the ethical principles applied to clinical decision making, the ethics of research, informing people of a serious infection and testing. These issues have already come up in evidence from those infected and affected as well as clinicians.

The group's expert opinion will help guide Sir Brian Langstaff to a decision on what ethical principles should have been applied in the 1970s and 80s.

### The Society to give evidence to inquiry

The Haemophilia Society begins two weeks of evidence at the inquiry in early February.

At the time of writing we do not know who will be a witness or what evidence will be examined – that is the choice of the inquiry. It is likely that evidence from our archives will be studied and that witnesses will be asked to talk about the charity's actions and advice during the 1970s, 80s and beyond.

Clive Smith, chair of The Society's board of trustees, said: "I give you my guarantee that today's Haemophilia Society will do all it can to help the inquiry get to the truth."

There will be a chance to discuss The Society's evidence at the end of the hearings in February. More details to follow.

### Psychological and practical support

Listening to evidence from clinicians has been difficult and has brought back painful and traumatic memories for many people.

If you are struggling with your feelings, please don't suffer alone. The Red Cross helpline for inquiry participants is available three days a week or you can leave a message and will be phoned back. Follow this [link](#).

### Merry Christmas and a Happy New Year

Wishing you all a Happy Christmas and a peaceful New Year. Always thinking of those missing from festive celebrations and family gatherings.

May memories of special times together give you hope and strength for the year ahead.

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## One mother's experience of listening to clinicians' evidence

### *'I needed to feel my son's life mattered'*

Rosemary Calder travelled to London to listen to the evidence of Professor Christine Lee, who was one of the clinicians to treat her son, Nicky. She found the experience very upsetting and, more than two months later, is still affected by Prof Lee's evidence as well as that of other clinicians.

Rosemary said: "There was no sign of remorse or regret for what happened to their patients, the people they were meant to be caring for. The damage is still being done to those of us that have to listen to people we had so much faith in, that we trusted our children's care and health to. I can't see how that person could be so unsympathetic and so uncompassionate."

Nicky, Rosemary's son, was infected with HIV and hepatitis C through his treatment for severe haemophilia. Rosemary was informed by letter that Nicky had tested positive for HIV in 1985 when he was 11. His diagnosis didn't stop him living as full a life as he could, inspiring others with his positive attitude. Nicky died, aged 25, in 1999.

Rosemary said: "We want to feel that that person matters, that their lives had some significance and some importance and for the clinician to show no sign of regret, it's almost as though they were totally

insignificant and it doesn't really matter what happened to them."

At the end of her evidence, Professor Lee, who worked at the Royal Free Haemophilia Centre from 1983-1984 and returned in 1987

before becoming its director in 1991, said the contaminated blood scandal was the "saddest tragedy of all". She also highlighted three patients whose lives had been transformed as a result of factor concentrates.

Rosemary felt Prof Lee's comments lacked sensitivity towards the hundreds of patients whose lives had been cut short or whose poor health had prevented them pursuing their dreams.

Rosemary said: ***"Nicky's passion was driving, that was all he ever wanted to do, he worked for his dad, he drove lorries, he moved huge machines on forklift trucks. For what it's worth, I want the world to know how proud I am of my son, of what he achieved and endured, as I know we all are proud of our loved ones."***

