

The Infected Blood Public Inquiry NEWSLETTER



THE
HAEMOPHILIA
SOCIETY

A summary of inquiry hearings

This week the inquiry has been looking at smaller haemophilia centres, predominantly in the north of England and Scotland. The presentations revealed large differences in treatment policies.

Sheffield Children's Hospital worked closely with the city's adult centre with no commercial factor used at all from 1982-85. One child—6% of patients—was infected with HIV. By contrast, in 1981 Leeds Haemophilia Centre was using three times as much commercial factor as NHS and no cryo at all except for vWD patients. Of its 90 haemophilia patients, 53—58%—were infected with HIV.

At the Royal Liverpool Hospital under Dr McVerry there was "insufficient" use of cryo and complaints that mild haemophilia patients were given factor with no discussion of the risks. HIV testing happened later than in other centres—some in 1986. One patient did not find out he was HIV positive until 1991 because the diagnosis had only been given to his foster father.

Manchester Children's Hospital told parents by letter of their child's HIV infection. Of its 42 haemophilia patients, 20—46%—were HIV positive.

Haemophilia B patients were consistently treated with NHS factor IX, across the centres featured.

Inquiry in focus: Alder Hey Children's Hospital

Alder Hey Children's Hospital had one of the highest HIV infection rates in the UK with about 90% (13) of its haemophilia A patients infected. The haemophilia centre was run by Dr Martin, an oncologist, until 1989 when haematologist, Dr Ball, arrived who was critical of its facilities and standards of care. The inquiry heard about the harrowing case of a boy with severe haemophilia A who was first treated with concentrate aged 2. Between 1982-1985 he was given 45 treatments from US commercial products and 9 NHS treatments. He also received 2 treatments of un-heat treated factor in 1985, the year he was diagnosed with HIV. The boy died in 1989. A report concluded that the failure to treat him with cryo had been "negligent". A mild/moderate boy was infected with HIV after having surgery to correct his "bat ears" in September 1983, with no risk warning given to his parents. A two-month-old baby was treated with factor concentrate, some of it commercial, from 1984 and was infected with HIV, along with his older brother. Jenni Richards said it "didn't seem to make any difference" whether NHS or commercial concentrate was used on children at Alder Hey at that time.

Quotes of the week

"For children...cryoprecipitate had many advantages, and for most admissions for joint bleeds, bumps and scrapes, heavy bruises, minor surgery was to be preferred, since it only exposed patients to a very small number of UK donors and reduced the risk of viral transmission that was becoming a recognised problem with large pool fractionation processing." Dr Lilleyman, Sheffield Children's Hospital 1975-95.

"It was as if the nurses had nothing but contempt for the patients. I would shower him when he was too weak to do it for himself and change his bed-sheets after he had soiled himself and was lying in the dirt for hours at a time." Statement on the care of her HIV-infected son at Royal Liverpool Hospital from an anonymous mother

"[Dr McVerry] informed me that he had not got AIDS..and to desist from telling him his job and stop being neurotic, to go home and get it out of my mind." Wife whose husband died of AIDS, aged 35, in 1985 who was treated at the Royal Liverpool Hospital.

"Alder Hey was like a conveyor belt of children dying." Mother of three sons, two of whom were infected with HIV and died.

"I would like to apologise on behalf of the Trust for the distress these shortcomings have caused to patients and their families who have suffered such trauma and tragedy and deserved better. I am truly and deeply sorry "

Erica Saunders, Alder Hey Hospital