

# The Infected Blood Public Inquiry NEWSLETTER



THE  
HAEMOPHILIA  
SOCIETY

## A summary of inquiry hearings

This week the inquiry's main focus has been on The Haemophilia Society (THS).

Peter Wetherell chaired his local group in Cambridge from 1981-83 and joined THS's executive committee from 83-85. Mr Wetherell, who had a son with haemophilia B, described how, in late 83, the penny began to drop about the impact of AIDS on the haemophilia community. He agreed that THS was

"too trusting" of the clinicians who advised the charity but added: "But what was the alternative? To whom would we go to get a counter-position?"

Simon Taylor, who has severe haemophilia A and is co-infected was a trustee at THS from 1985-88, 1991-96 and 1998-2002.

THS's decision to pursue a "moral" and not legal case in its campaign to get support for haemophiliacs with HIV in

1987 was questioned. Mr Taylor said urgent help was needed and a court case could have dragged on for years.

During his time at THS six fellow trustees died of AIDS, as did six school friends. Mr Taylor said haemophilia at the time became a "marker for AIDS" with terrible stigma and discrimination.

\*There was also a presentation on ethical and professional guidance for clinicians.

## Inquiry news in focus: hepatitis C campaign

In 1995 THS began its campaign for recompense for people with haemophilia infected with hepatitis C, which was based on the government's "moral" responsibility. It was almost a decade before the government conceded that support was needed, resulting in The Skipton Fund. Karin Pappenheim, chief executive of THS from 1998-2004 told the inquiry that throughout her tenure she had to deal with "tensions" between funding campaign work related to contaminated blood and maintaining the charity's other services. In 2002 she urged trustees to be "careful" as the campaign was set to cost £230,000 by the end of that year and was drawn mainly from THS reserves. Simon Taylor, then Treasurer, said THS was "banging its head against a brick wall" and did not feel the cost of the campaign could still be justified. Spending had increased with the appointment of PR consultants to give an extra push to the campaign. In 2002 it was agreed to scale it back, although the campaign continued. Ms Pappenheim also faced criticism that some members infected with HIV felt overlooked at that time in favour of non-infected families, which she said was an "inaccurate" perception.

## Quotes of the week

"[There was] the awful possibility that the damage had been done, that somehow or other the grim reaper was lurking in the room." Peter Wetherell, on his realisation in Oct 1983 that AIDS was infecting haemophiliacs

"I am not convinced that a public inquiry would provide greater insight into the problem or pave the way for any further improvements in the safety controls which are now in place."  
Prime Minister Tony Blair, 1999

"There was...certainly not in my mind, any sense that we wished to prioritise one group over another, but we were trying to do a very challenging thing as a smallish charity and meeting all of those needs." Karin Pappenheim on whether she wanted to move focus away from people with HIV in favour of services for families.

"It was totally insufficient, inadequate amount of money but it was a foot in the door. It was a recognition of the moral case that we had put and that we would be back for more."

Simon Taylor on the government's allocation of £10m in 1987 for people with haemophilia infected with HIV after a campaign by The Haemophilia Society

"I would contend that for such a small charity...what was achieved was truly remarkable and is a testament to the staff and volunteers involved, and my thanks goes to all those over the years who have kept this issue alive."

Simon Taylor on The Haemophilia Society