SMALLER HAEMOPHILIA CENTRES

MILTON KEYNES HAEMOPHILIA CENTRE

The Centre

1. The Milton Keynes Haemophilia Centre is an inactive haemophilia centre designated as centre number 34.[1] It was part of the Oxford Supraregion. Drs Donald Moir and Elizabeth J Miller were Directors of the Centre in the 1980s and 1990s, but the precise dates are unclear.

Number of patients treated

2. There is no available annual return from the Centre prior to 1989.

Blood products used

3. This is no available record of blood products used by the Centre prior to 1989.

Knowledge of risk of hepatitis/AIDS and HTLV-III

4. On 27 February 1985, a letter from Dr A E Dike (Senior Medical Officer) to Dr Moir indicates that a patient at the Centre tested positive for HBsAg and anti-HBE on a routine screening.[2]

5. UKHCDO minutes show that Dr Miller attended UKHCDO meetings on 9 October 1981 (then representing Hillingdon Hospital),[3] 27 September 1984,[4] 25 September 1987[5] and subsequent meetings in the 1990s. It may be reasonable to assume that as Director of the Milton Keynes Centre, Dr Miller would have received copies of the reports circulated for, and the minutes of, UKHCDO meetings that she did not attend.

---

[1] HCDO0000637
[2] NHBT0087102
[3] DHSC0001312
[4] PRSE0003659
[5] CBLA0002386

Testing for HIV/HCV and numbers of patients infected

6. UKHCDO data available to the Inquiry suggests that 0 people were identified at the Centre as infected with HIV between 1979 and 1991.[6]

7. In 1988, Dr Miller was involved in the care of a teenage patient with haemophilia A who was HIV positive; his parents were aware of the diagnosis, but he was not. Dr Miller consulted Dr Goldman at the Royal Free Hospital regarding his case.[7]

8. An Inquiry witness who was under the care of Dr Miller at Milton Keynes Hospital (MKH) for von Willebrand's disease recalls discovering that she was tested for HIV without consent: "*When I was working in the GUM clinic in MKH in or about 2006, I saw a list as long as my arm for HIV tests that they had carried out on me. I was never asked to sign anything and I did not know that they were testing me for HIV*".[8] She also recalls that little information was provided to her when she was told of her positive hepatitis C status:

> "*When they sent me the piece of paper, which stated that I was Hep C positive, I was not provided with any further information as to how dangerous the infection was or what treatment was available. ... I was only given adequate information for Hep C when the doctors realised how serious it was, but this was approximately ten years after I had been infected. I do recall Dr Miller talking to me about possible treatment that is available, which I initially declined. I believe information should have been provided to me earlier*".[9]

Other information

9. Following the introduction of a new concentrate of factor VIII in 1985, the Centre collaborated in the 'Confirmation of viral safety of dry heated Factor VIII concentrate (8Y) prepared by Bio Products Laboratory (BPL)' study, which concluded that "*heating this large-pool concentrate to 80°C for 72 hours in the final vial prevented transmission of HCV*".[10] Patients who entered the study were those without previous

[6] INQY0000250; WITN3826020
[7] DHSC0022342_001
[8] WITN1249001 para 22
[9] WITN1249001 paras 15-16
[10] BPLL0006083

exposure to blood or any blood product. Before treatment with 8Y, they were tested negative for anti-HIV-1, anti-HBsAg and anti-HBs, and their ALT and/or AST levels were confirmed to be within the normal range. It is stated that "*informed consent was obtained from all patients*". Patients were also tested for anti-HCV at a later stage of the study when tests became available, which confirmed that no patient acquired HCV infection.

10. Among those patients of the Centre who entered the above study was a boy with severe haemophilia A. In a letter from Dr Miller to Dr C Rizza at the Oxford Haemophilia Centre dated 8 May 1988, Dr Miller noted that "*This is the first time [he] has been exposed to blood products and because of the risk of non-A, non-B hepatitis we will be keeping a close eye on him and doing serial liver function tests every two weeks for the next few months*".[11] However, the boy was withdrawn from the study soon after receiving his first and second exposure to 8Y due to "*extensive swelling and bruising in the right ante-cubital fossa*" and "*poor venous access*".[12]

EUGENE TANG
Inquiry Legal Team

JENNI RICHARDS KC
RACHEL BARRETT
Inquiry Counsel Team
January 2023

[11] OXUH0002110_007
[12] OXUH0002110_006