

SMALLER HAEMOPHILIA CENTRES PRESENTATION
ROYAL STOKE HOSPITAL (FORMERLY NORTH STAFFORDSHIRE HOSPITAL),
STOKE-ON-TRENT

Directors

1. The director of the Haemophilia Centre at Stoke/North Staffordshire Hospital (Centre number 24) from 1976 to 2004 was Dr Robert Ibbotson where he was a consultant haematologist.¹ Dr Ibbotson has provided a written statement to the Inquiry dated 9 March 2021.² He stated that, in his absence, cover was provided by Dr P M Chipping. Dr Chipping has provided a written statement to the Inquiry dated 9 November 2020.³ She was a consultant haematologist at Stoke/North Staffordshire Hospital from December 1982 to June 2009.⁴
2. Dr Ibbotson described his own role as *“To provide treatment and advice to patients with bleeding disorders, later on as management of complication of viral infection”*.⁵ Dr Chipping was unable to provide a history of the Haemophilia Centre at Stoke but assumed it was set up by her predecessor Dr Chris Giles and subsequently largely run by her colleague Dr Ibbotson.⁶ She stated that although she was nominally co-director of the Haemophilia Centre and assisted in completing the annual returns, she *“had little involvement with the day to day treatment of patients with haemophilia”*.⁷ She stated *“My own role at Stoke involved the treatment of patients with malignant haematological conditions and I was only involved with the treatment of haemophilia and other bleeding disorder patients when covering for my colleague during weekends and periods of annual leave”*.⁸ She explained that:⁹

¹ WITN4678001 para 2

² WITN4678001

³ WITN4567001

⁴ WITN4567001 para 5.6

⁵ WITN4678001 para 5(b)

⁶ WITN4567001 para 13

⁷ WITN4567001 para 13

⁸ WITN4567001 para 13

⁹ WITN4567001 para 14

“Dr Ibbotson took the lead in managing patients with bleeding orders. I believe that he would be better placed than I am to provide further information about treatment of bleeding disorder patients in Stoke.”

3. Dr Ibbotson described the Centre as follows:¹⁰

“Established in 1975 to provide follow up and treatment of patients with bleeding disorders and later on thrombotic conditions. Then known as the North Staffordshire Haemophilia Centre.”

4. The facilities at Stoke/North Staffs Hospital in 1974 were described in *“Treatment of Haemophiliacs Summary of Workload 1974”*¹¹ for the West Midlands Regional Health Authority:

“Facilities

- (i) 24 hour telephone advisory service*
- (ii) Specialist consultant service for surgical, dental, physiotherapy and social care*
- (iii) Reference Laboratory service for factor assays, inhibitor [sic] titres etc.*
- (iv) Educational facilities for patients, medical and para-medical staff.*
- (v) Available factor concentrates: cryoprecipitate, freeze-dried factor VIII and freeze-dried factor IX.”*¹²

Status of Haemophilia Centre, Relationship with other Haemophilia Centres, Relationship with Regional Transfusion Centre

5. The Haemophilia Centre at Stoke-on-Trent was based at the Department of Haematology, Central Pathology Laboratory, Hartshill Road, Hartshill,

¹⁰ WITN4678001 para 5(a)

¹¹ SHIN0000045 p. 5

¹² SHIN0000045 p. 6

Stoke-on-Trent, Staffordshire ST4 7PX (“Stoke Hospital” or “North Staffs/Staffordshire Hospital”).¹³ The designated Haemophilia Centre Number was 24.

6. In 1975/1976, Stoke/North Staffs Hospital was part of the West Midlands Regional Health Authority.¹⁴ Other Haemophilia Centres in the West Midlands Region included Birmingham Queen Elizabeth’s, Birmingham Children’s, Hereford, Coventry, Shrewsbury, Worcester and Wolverhampton.
7. Dr Ibbotson was a member and secretary of the West Midlands RHA Working Party on the Treatment of Haemophiliacs (“Working Party”).¹⁵ He regularly attended meetings of the Working Party including on 22 November 1976,¹⁶ 23 May 1977,¹⁷ 21 November 1977,¹⁸ 15 May 1978,¹⁹ 4 December 1978,²⁰ 14 May 1979,²¹ 19 May 1980,²² 8 December 1980,²³ 22 June 1981,²⁴ 23 November 1981,²⁵ 28 June 1982,²⁶ 5 December 1983,²⁷ 14 May 1984,²⁸ 29 October 1984,²⁹ 17 December 1984,³⁰ 15 February 1985,³¹ 13 May 1985,³² 29 July 1985,³³ 2 December 1985,³⁴ 24 March 1986,³⁵ 14 July 1986,³⁶ 13 October 1986,³⁷ 10 November 1986,³⁸ 15 December 1986,³⁹ 2

¹³ DHSC0002263_005, p. 16 (14 on the document)

¹⁴ OXUH0000863_002

¹⁵ WITN4678001 para 3

¹⁶ SHIN0000043

¹⁷ SHIN0000042

¹⁸ SHIN0000041

¹⁹ SHIN0000040

²⁰ CBLA0000882

²¹ SHIN0000038

²² SHIN0000036

²³ SHIN0000035

²⁴ SHIN0000034

²⁵ SHIN0000033

²⁶ SHIN0000032

²⁷ SHIN0000029

²⁸ SHIN0000028

²⁹ SHIN0000027

³⁰ SHIN0000026_002

³¹ SHIN0000025

³² SHIN0000024

³³ SHIN0000023

³⁴ SHIN0000022

³⁵ SHIN0000021_001

³⁶ SHIN0000020

³⁷ SHIN0000019

³⁸ SHIN0000018_001

³⁹ SHIN0000017

March 1987,⁴⁰ 6 April 1987,⁴¹ 27 July 1987,⁴² 14 September 1987,⁴³ 30 November 1987,⁴⁴ 16 May 1988,⁴⁵ 18 July 1988,⁴⁶ 17 October 1988,⁴⁷ 13 February 1989,⁴⁸ 10 April 1989,⁴⁹ 6 November 1989,⁵⁰ 5 February 1990,⁵¹ 16 July 1990,⁵² and 24 January 1991.⁵³

8. At a meeting of the Working Party on 13 May 1976,⁵⁴ Stoke was reported to be a designated Haemophilia Centre (not an Associate Centre):

“Dr Stewart reported for information that he had officially notified the DHSS that three centres The Queen Elizabeth and Childrens Hospitals jointly, Stoke and Coventry, had been designated Haemophilia Centres, whilst Shrewsbury, Worcester, Hereford and Wolverhampton were to be designated Associate Centres.”

9. It is understood that Stoke/North Staffs Hospital was supplied by the Regional Transfusion Centre in Birmingham which supplied the whole of the West Midlands Region.⁵⁵ According to Dr Ibbotson, all blood products were provided by the Regional Blood Transfusion Centre in Birmingham.⁵⁶

10. Stoke/North Staffs Hospital, along with other Haemophilia Centres in the West Midlands Region, was part of the Oxford Haemophilia Supraregion. Dr Ibbotson attended meetings of Haemophilia Centre Directors and Blood Transfusion Centre

⁴⁰ SHIN0000016

⁴¹ SHIN0000015_001

⁴² SHIN0000014

⁴³ SHIN0000013

⁴⁴ SHIN0000012

⁴⁵ SHIN0000011_002

⁴⁶ SHIN0000010

⁴⁷ SHIN0000009

⁴⁸ SHIN0000008

⁴⁹ SHIN0000007

⁵⁰ SHIN0000006

⁵¹ SHIN0000005

⁵² SHIN0000004

⁵³ SHIN0000003

⁵⁴ SHIN0000044, p.2

⁵⁵ WITN3808005 para 6.1 and WITN4567001 para 16

⁵⁶ WITN4678001 para 28

Directors within the Oxford Haemophilia Supraregion on 26 July 1976,⁵⁷ and 19 June 1978,⁵⁸ At the meeting on 26 July 1976,⁵⁹ It was recorded that the “*Oxford Haemophilia Reference Centre had responsibility for the care of haemophiliacs in the Health Authority Regions:- West Midlands, Oxford, Wessex, the South West and Northern Ireland*”. It appears that a further meeting was scheduled for 22 October 1985,⁶⁰ for which Dr Ibbotson sent his apologies,⁶¹ but minutes of the meeting have so far not been located.

Number of Patients Treated and/or Registered at the Centre

11. Dr Ibbotson stated:⁶²

“Between 20-30 patients were registered. No children were treated by me as I had no paediatric training. My understanding was they were referred to Birmingham Children’s Hospital.”

12. According to a note on “*Treatment of Haemophiliacs Summary of Workload 1974*” for the West Midlands Regional Health Authority,⁶³ the number of patients registered at Stoke/North Staffs Hospital in 1974 was 71. 22 patients (15 patients with haemophilia A, 3 patients with Christmas disease, 3 patients with von Willebrand’s disease, and 1 patient with Hypofibrinogenemia) were treated at the Centre.⁶⁴

13. A list of Haemophilia Centres in around 1975 suggests that there were 7 patients with haemophilia A at Stoke/North Staffs Hospital.⁶⁵

⁵⁷ CBLA0000391

⁵⁸ OXUH0003752_005

⁵⁹ CBLA0000391

⁶⁰ OXUH0003752_026 and OXUH0003752_002

⁶¹ OXUH0003752_025

⁶² WITN4678001 para 6

⁶³ SHIN0000045, p. 5

⁶⁴ SHIN0000045 p. 6

⁶⁵ OXUH0000863_002, p.1

14. In the following years, the numbers of patients registered and/or treated at Stoke/North Staffs from the available evidence were as follows:

15. 1976: The Annual Returns for 1976, signed by Dr Ibbotson, show that the Centre treated 10 patients with haemophilia A,⁶⁶ 4 patients with Christmas disease,⁶⁷ and 2 patients with von Willebrand's disease.⁶⁸ Of 10 patients with haemophilia A, it appears that 2 patients were on regular home therapy.⁶⁹ Of 4 patients with Christmas disease, it appears that 1 patient was on regular home therapy.⁷⁰

16. 1977: The Annual Returns for 1977, signed by Dr Ibbotson, show that the Centre treated 16 patients with haemophilia A,⁷¹ and 3 patients with Christmas disease.⁷² It appears that 2 patients with haemophilia A were on regular home therapy.⁷³ Of 3 patients with Christmas disease, it appears that 1 patient was on regular home therapy.

⁷⁴

17. The Inquiry has been unable to locate the Annual Returns for 1978.

18. 1979: The Annual Returns for 1979, signed by Dr Ibbotson, show that the Centre treated 16 patients with haemophilia A,⁷⁵ 2 patients with Christmas disease,⁷⁶ and 2 patients with von Willebrand's disease.⁷⁷ Of 16 patients with haemophilia A, it appears that 5 patients were on regular home therapy.⁷⁸ Of 2 patients with Christmas disease, it appears that 1 patient was on regular home therapy.⁷⁹

⁶⁶ HCDO0001121 p. 1

⁶⁷ HCDO0001121 p. 1

⁶⁸ HCDO0001121 p. 2

⁶⁹ HCDO0001121 p. 3

⁷⁰ HCDO0001121 p. 4

⁷¹ HCDO0001207 p. 1

⁷² HCDO0001207 p. 1

⁷³ HCDO0001207 pp. 3-4

⁷⁴ HCDO0001207 p. 2

⁷⁵ HCDO0001356 p. 1

⁷⁶ HCDO0001356 p. 1

⁷⁷ HCDO0001356 p. 8

⁷⁸ HCDO0001356 pp. 3-4

⁷⁹ HCDO0001356 p. 5

19. 1980: The Annual Returns for 1980, signed by Dr Ibbotson, show that the Centre treated 14 patients with haemophilia A,⁸⁰ and 2 patients with haemophilia B.⁸¹
20. 1981: The Annual Returns for 1981, signed by Dr Ibbotson, show that the Centre treated 14 patients with haemophilia A,⁸² 3 patients with Christmas disease,⁸³ and 1 patient with von Willebrand's disease.⁸⁴
21. 1982: The Annual Returns for 1982, signed by Dr Ibbotson, do not clearly show the number of patients treated at the Centre during that year.
22. 1983: The Annual Returns for 1983, signed by Dr Ibbotson, show that the Centre treated 21 patients with haemophilia A,⁸⁵ 4 patients with haemophilia B,⁸⁶ and 1 patient with von Willebrand's disease.⁸⁷
23. 1984: The Annual Returns for 1984, signed by Dr Ibbotson, show that the Centre treated 17 patients with haemophilia A,⁸⁸ 4 patients with haemophilia B,⁸⁹ and 1 patient with von Willebrand's disease.⁹⁰
24. 1985: The Annual Returns for 1985, signed by Dr Ibbotson, show that the Centre treated 14 patients with haemophilia A,⁹¹ 3 patients with haemophilia B,⁹² and 0 patients with von Willebrand's disease.⁹³

⁸⁰ HCDO0001453 p. 1

⁸¹ HCDO0001453 p. 3

⁸² HCDO0001577 p. 1

⁸³ HCDO0001577 p. 2

⁸⁴ HCDO0001577 p. 1

⁸⁵ HCDO0001769 p. 1

⁸⁶ HCDO0001769 p. 3

⁸⁷ HCDO0001769 p. 1

⁸⁸ HCDO0001863 p. 1

⁸⁹ HCDO0001863 p. 2

⁹⁰ HCDO0001863 p. 1

⁹¹ HCDO0001958 p. 1

⁹² HCDO0001958 p. 2

⁹³ HCDO0001958 p. 1

25. 1986: The Annual Returns for 1986, signed by Dr Ibbotson, show that the Centre treated 18 patients with haemophilia A,⁹⁴ 4 patients with haemophilia B,⁹⁵ and 3 patients with von Willebrand's disease.⁹⁶

26. It appears that data from Stoke/North Staffs was contributed by Dr Ibbotson and Dr Giles to published studies including: "*Treatment of haemophilia and related disorders in Britain and Northern Ireland during 1976-80*" by C R Rizza and Rosemary J D Spooner.⁹⁷

Treatment policies and blood product usage

27. Dr Ibbotson stated that decision-making about the selection and purchase of blood products was a regional decision which he was not directly involved with.⁹⁸ He stated that he believed BPL, Cutter and Armour products were used.⁹⁹ Dr Ibbotson stated that he tried to give the British product to all patients if it was available.¹⁰⁰

28. Dr Chipping stated that the supply of blood products was the role of the Regional Transfusion Centre, and that Stoke was supplied by the West Midlands Blood Transfusion Centre.¹⁰¹ She explained:¹⁰²

"Decisions about ordering were made on the basis of clinical need but issue of products depended on their availability at the RTC. Whilst we ordered British produced Factor concentrates on the basis that we were aware the commercial products might contain plasma from paid donors, supplies of Factor VIII concentrate from the Blood Product Laboratory (BPL) were limited and until well into the 1980s it was unusual to receive what we had ordered, substitution

⁹⁴ HCDO0000330_004 p. 1

⁹⁵ HCDO0000330_004 p. 4

⁹⁶ HCDO0000330_004 p. 1. The Annual Returns for 1987 are at HCDO0002142; 1988 at HCDO0002234; 1989 at HCDO0002327 and 1990 at HCDO0002417.

⁹⁷ HCDO0000586

⁹⁸ WITN4678001 para 7

⁹⁹ WITN4678001 para 8

¹⁰⁰ WITN4678001 para 8

¹⁰¹ WITN4567001 para 16

¹⁰² WITN4567001 para 16

being made with commercial factor VIII. As supply was via the RTCs, financial considerations were not a factor in our decision-making process. This is true even when cross charging for blood products was introduced.”

29. According to data contained in the Annual Returns, Stoke-on-Trent used the following blood products:

30. 1976: To treat 10 patients with haemophilia A, the Centre used a variety of products:

103

- a. 774 bottles / 54,180 units of cryoprecipitate;
- b. 263 bottles / 60,490 units of NHS factor VIII;
- c. 12 bottles / 3,528 units of Armour Factor VIII (Factorate);
- d. 1 bottle / 300 units of Cutters Factor VIII (Koate); and
- e. 4 bottles / 1,176 units of Immuno Factor VIII (Kryobulin).

31. To treat 4 patients with Christmas disease, the Centre used 75 bottles / 45,000 units of NHS factor IX.¹⁰⁴ To treat 2 patients with von Willebrand's disease, the Centre used:

105

- a. 47 bottles / 3,290 units of cryoprecipitate;
- b. 17 bottles / 3,910 units of NHS factor VIII; and
- c. 4 bottles / 1,200 units of Immuno Factor VIII.

32. 1977: To treat 16 patients with haemophilia A, the Centre used a variety of products:

106

- a. 1,948 bottles / 155,840 units of cryoprecipitate;
- b. 70 bottles / 14,745 units of NHS factor VIII;

¹⁰³ HCDO0001121 p. 1

¹⁰⁴ HCDO0001121 p. 1

¹⁰⁵ HCDO0001121 p. 2

¹⁰⁶ HCDO0001207 p. 1

- c. 20 bottles / 5,880 units of Armour Factor VIII (Factorate); and
- d. 4 bottles / 1,200 units of Immuno Factor VIII (Kryobulin).

33. To treat 3 patients with Christmas disease, the Centre used 62 bottles / 37,450 units of NHS factor IX.¹⁰⁷

34. 1979: To treat 16 patients with haemophilia A, the Centre used:¹⁰⁸

- a. 539 bottles / 44,000 units of cryoprecipitate;
- b. 115 bottles / 26,645 units of NHS factor VIII; and
- c. 31 bottles / 7,487 units of Armour Factor VIII (Factorate).

35. To treat 2 patients with Christmas disease, the Centre used 49 bottles / 31,605 units of NHS factor IX.¹⁰⁹ To treat 2 patients with von Willebrand's disease, the Centre used:

110

- a. 41 bottles / 3,200 units of cryoprecipitate;
- b. 6 bottles / 1,560 units of NHS factor VIII; and
- c. 1 bottle / 462 units of Armour Factor VIII.

36. 1980: To treat 14 patients with haemophilia A, it appears that the Centre used:¹¹¹

- a. 30,000 units of cryoprecipitate in hospital;
- b. 40,500 units of NHS factor VIII in hospital and 56,000 units of NHS factor VIII for home treatment; and
- c. 34,320 units of Armour Factor VIII (Factorate) in hospital and 14,800 units of Armour Factor VIII for home treatment.

¹⁰⁷ HCDO0001207

¹⁰⁸ HCDO0001356 p. 1

¹⁰⁹ HCDO0001356 p. 1

¹¹⁰ HCDO0001356 p. 8

¹¹¹ HCDO0001453 p. 1. The figures are faint and somewhat difficult to read

37. To treat 2 patients with haemophilia B, the Centre used 52,940 units of NHS factor IX in hospital and 28,540 units of NHS factor IX for home treatment.¹¹²

38. 1981: To treat 14 patients with haemophilia A, the Centre used:¹¹³

- a. 24,720 units of cryoprecipitate in hospital;
- b. 83,790 units of NHS factor VIII in hospital and 52,775 units of NHS factor VIII for home treatment; and
- c. 4,995 units of Armour Factor VIII (Factorate) in hospital and 2,295 units of Armour Factor VIII for home treatment.

39. To treat 3 patients with haemophilia B, the Centre used 40,800 units of NHS factor IX in hospital and 31,200 units of NHS factor IX for home treatment.¹¹⁴ To treat 1 patient with von Willebrand's disease, the Centre used 570 units of NHS factor VIII.¹¹⁵

40. 1982: To treat patients with haemophilia A, the Centre used:¹¹⁶

- a. 2 bags / 800 units of plasma in hospital;
- b. 240 bags / 16,800 units of cryoprecipitate in hospital;
- c. 33,540 units of NHS factor VIII in hospital and 47,230 units of NHS factor VIII for home treatment; and
- d. 17,255 units of Armour Factor VIII (Factorate) in hospital and 15,790 units of Armour Factor VIII for home treatment.

41. To treat patients with haemophilia B, the Centre used 19,460 units of NHS factor IX in hospital and 64,425 units of NHS factor IX for home treatment.¹¹⁷ To treat patients

¹¹² HCDO0001453 p. 3

¹¹³ HCDO0001577 p. 1

¹¹⁴ HCDO0001577 p. 2

¹¹⁵ HCDO0001577 p. 1

¹¹⁶ HCDO0001673 p. 1

¹¹⁷ HCDO0001673 p. 2

with von Willebrand's disease, the Centre used 18 bags / 1,260 units of cryoprecipitate and 19,320 units of NHS factor VIII in hospital.¹¹⁸

42. 1983: To treat 21 patients with haemophilia A, the Centre used:¹¹⁹

- a. 728 bags / 58,240 units of cryoprecipitate in hospital;
- b. 185,746 units of NHS factor VIII in hospital and 112,785 units of NHS factor VIII for home treatment; and
- c. 29,385 units of Armour Factor VIII (Factorate) in hospital and 2,400 units of Armour Factor VIII for home treatment.

43. To treat 4 patients with haemophilia B, the Centre used 116,365 units of NHS factor IX in hospital and 76,395 units of NHS factor IX for home treatment.¹²⁰ To treat 1 patient with von Willebrand's disease, the Centre used 5 bags / 400 units of cryoprecipitate.¹²¹

44. 1984: To treat 17 patients with haemophilia A, the Centre used:¹²²

- a. 383 bags / 26,810 units of cryoprecipitate in hospital;
- b. 34,700 units of NHS factor VIII in hospital and 133,225 units of NHS factor VIII for home treatment; and
- c. 5,850 units of Armour Factor VIII (Factorate) in hospital and 21,610 units of Armour Factor VIII for home treatment.

45. To treat 4 patients with haemophilia B, the Centre used 12,000 units of NHS factor IX in hospital and 88,000 units of NHS factor IX for home treatment.¹²³ To treat 1 patient

¹¹⁸ HCDO0001673 p. 1

¹¹⁹ HCDO0001769 p. 1

¹²⁰ HCDO0001769 p. 3

¹²¹ HCDO0001769 p. 1

¹²² HCDO0001863 p. 1

¹²³ HCDO0001863 p. 2

with von Willebrand's disease, the Centre used 148 bags / 10,360 units of cryoprecipitate and 3,500 units of NHS factor VIII in hospital.¹²⁴

46. 1985: To treat 14 patients with haemophilia A, the Centre used:¹²⁵

- a. 729 packs / 51,030 units of cryoprecipitate in hospital;
- b. 3,425 units of Armour Factor VIII (Factorate) in hospital and 113,020 units of Armour Factor VIII for home treatment; and
- c. Unknown quantities of NHS factor VIII.

47. To treat 3 patients with haemophilia B, the Centre used 31,540 units of NHS factor IX in hospital and 74,150 units of NHS factor IX for home treatment.¹²⁶

48. 1986: To treat 18 patients with haemophilia A, the Centre used:¹²⁷

- a. 68 bags of cryoprecipitate in hospital;
- b. 8,700 units of NHS factor VIII in hospital and 170,615 units of NHS factor VIII for home treatment;
- c. 1,770 units of Alpha Factor VIII (Profilate) in hospital and 23,950 units of Alpha Factor VIII for home treatment;
- d. 750 units of Armour Factor VIII (Factorate) in hospital and 36,345 units of Armour Factor VIII for home treatment; and

49. To treat 3 patients with von Willebrand's disease in hospital, the Centre used 160 bags of cryoprecipitate.¹²⁸ To treat 4 patients with haemophilia B, the Centre used 5,230 units of NHS factor IX in hospital and 122,820 units of NHS factor IX for home treatment.¹²⁹

¹²⁴ HCDO0001863 p. 1

¹²⁵ HCDO0001958 p. 1

¹²⁶ HCDO0001958 p. 2

¹²⁷ HCDO0000330_004 p. 1

¹²⁸ HCDO0000330_004 p. 1

¹²⁹ HCDO0000330_004 p. 4

50. In relation to home treatment, Dr Ibbotson stated, *“Patients were keen on home treatment especially as it was supported by the Haemophilia Society”*.¹³⁰ In relation to prophylactic treatment, Dr Ibbotson stated, *“It was left to the decision of the Haemophiliacs if they wanted to embark on prophylactic treatment. They worked out their usage”*.¹³¹

51. In relation to the risks of blood products, Dr Ibbotson stated, *“Patients were informed of the risk and it was suggested that an attempt [be] made to reduce the use of concentrates”*.¹³² Dr Ibbotson reiterated again that *“All patients were informed of infection risks. They had been before commencing on Factor VIII concentrate”*.¹³³ Dr Ibbotson also added, *“The patients knew my views on blood products”*.¹³⁴ He added that, *“All patients gave consent verbally to me. Only one patient was treated without consent. He was unconscious having fallen down the stairs”*.¹³⁵

52. The Inquiry has received evidence from an anonymous witness who was diagnosed with haemophilia B.¹³⁶ The witness had two teeth removed in 1972 and had intermittent bleeding.¹³⁷ She was referred to Dr Ibbotson at the Royal Stoke Hospital on 14 March 1980 and he tested her for haemophilia.¹³⁸ She stated that when she was diagnosed with haemophilia, she *“was not given any advice about the condition”*. She stated that *“Dr Ibbotson seemed thrilled that somebody in [redacted] had haemophilia B”*.¹³⁹ The witness received factor IX products on several occasions and later contracted hepatitis C.

53. The witness first received factor IX product during a tooth extraction on 22 July 1980.

¹⁴⁰ She stated:

¹³⁰ WITN4678001 para 15

¹³¹ WITN4678001 para 16

¹³² WITN4678001 para 22

¹³³ WITN4678001 para 27

¹³⁴ WITN4678001 para 36(a)

¹³⁵ WITN4678001 para 58

¹³⁶ WITN3160001 para 3

¹³⁷ WITN3160001 para 7

¹³⁸ WITN3160001 para 7

¹³⁹ WITN3160001 para 7

¹⁴⁰ WITN3160001 para 11

“At the time, I did not know I was being given a blood product, as it was a white liquid and I was not told what it was. I had believed it was a liquid form of the tablets I had previously been given to control bleeding. I was never told there might be a risk of infection from receiving Factor IX product. Following the tooth extraction, they plugged the socket and stitched it, as a precaution.”

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54. The witness received factor IX product for a second time in 1987. She described:¹⁴²

“13. On 14 August 1987 I had a dilation and curettage (“D&C”) procedure because I had gynaecological issues. I went to the RSH [Royal Stoke Hospital] for this procedure and I received Factor IX product for the second time. I had not received any blood products between 1980 and 1987. At the time, I was told that Factor IX was a product which would help my blood to clot, and I was told I needed to have it before I had the D&C procedure.

14. At the time I went into the RSH for this procedure, HIV was a prevalent topic in the media. Consequently, I told the doctors I did not want Factor IX products, as I thought there was a risk of being infected, from what I had seen in the media. I asked the doctors about the risk of being infected with HIV and they told me there was a 99.9% chance I would not contract anything. At the time, I was not aware of Hepatitis C, and so it was HIV that I was concerned about. I was told everything would be alright, but I still did not want to have Factor IX. I told the doctor that I did not need Factor IX for the D&C procedure, as I only bleed more than an average person when something is pulled or torn, for example teeth extraction and major operations.

15. Prior to the procedure, a doctor came into to give me my pre-medication at around 13.15 hours. The procedure was scheduled for 14.00 hours. At around 13.45 hours, I was told the doctor scheduled to perform the procedure, Mr

¹⁴¹ WITN3160001 para 12

¹⁴² WITN3160001 paras 13-17

Menon, indicated he would not do it unless I took the Factor XI. By that time, I was quite drowsy from the pre medication and I had no real option; they gave me Factor IX despite my previous refusal.

16. I do not believe I was given a real choice about whether to have Factor IX for the D&C procedure. I had refused it, and the doctors had waited until I was drowsy before giving the treatment to me anyway. According to the Report, "there is a record that 1,290iu of heat treated Factor IX concentrate was given. No abnormal bleeding occurred."

17. I reacted very badly to the Factor IX I was given in 1987 and I was unwell for several weeks. My energy levels fell and I was frequently sweating; my health was deteriorating. I phoned Dr Ibbotson for an urgent appointment and he told me it could be "a Hepatitis attack", even though I was not jaundiced. He did not mention this would be a permanent condition; he made it sound as though it would go away. He may have called it "Non-A Non-B Hepatitis". The Report, based on my medical records, confirms this [WITNXXXX002]¹⁴³. I was not tested for any type of Hepatitis at the time so I do not know what made him think the symptoms could be caused by Hepatitis. Dr Ibbotson had been on holiday when I had my D&C procedure. When he returned he told me that had he been available at the time of my procedure, he would have said it could go ahead without Factor IX cover."

55. The witness has continued to receive factor products since 1987.¹⁴⁴

"Since 1987, I have continued to have factor products for teeth extractions. Dentists will not remove my teeth unless I have factor cover. Now I would have recombinant factor (a synthetic product) if I required an operation or a tooth extraction."

¹⁴³ WITN3160002

¹⁴⁴ WITN3160001 para 21

56. The witness believed that she contracted hepatitis C from her tooth extraction in 1980. She stated:¹⁴⁵

“I understand it was during the tooth extraction in 1980, when I was given Factor IX, that I contracted Hepatitis C. The Report confirms “there is now no doubt that the treatment given in 1980 would have transmitted Non-A Non-B Hepatitis (now Hepatitis C) but there was no agreement at the time that all patients should be warned of the risk (which was not yet fully known)... the illness of 1987 nine days after D&C cannot be confirmed as being due to acute attack of Hepatitis and I have no doubt that if frozen samples are available it would be possible to demonstrate that Hepatitis C infection took place in 1980.” ...”

57. She reiterated in her statement:¹⁴⁶

“As I have referred to at paragraphs 15 and 16 above, I did not consent to receiving Factor IX products either during the tooth extraction in 1980 or during my D&C procedure in 1987. In 1980 I was not told anything about the white liquid I was given, neither what it was nor any risks of taking it. In 1987 I was aware that HIV could be contracted through blood products, which was often reported by the media, and I had specifically said I did not want Factor IX products, unfortunately, those wishes were overridden, as I was approached in a drowsy state just before the procedure, and I was given Factor IX for the second time.”

Knowledge of risk of hepatitis and response to risk

58. In relation to knowledge of risk of hepatitis, Dr Ibbotson stated:¹⁴⁷

¹⁴⁵ WITN3160001 para 29

¹⁴⁶ WITN3160001 para 32

¹⁴⁷ WITN4678001 para 18

“It was apparent to me that all blood and blood products had a hepatitis risk of non A and non B. The greater the number of donors the greater the risk. Over time is becoming apparent that my views were correct and I did not change them.”

59. In relation to risk of infection, Dr Ibbotson stated that he *“considered the use of commercial Factor VIII at higher risk than UK Factor VIII as the history of the donors was limited compared to UK donors. Hence my effort always to receive UK material”*.¹⁴⁸

60. In response to risk of infection, Dr Ibbotson stated that:¹⁴⁹

“All patients were offered local treatment with cryoprecipitate. Those on home treatment preferred Factor VIII and by the time the full information of HIV was available supplies of heat treated factor VIII were on stream.”

61. It appears that Dr Ibbotson attended several meetings of UKHCDO including on 13 January 1977,¹⁵⁰ 24 October 1977,¹⁵¹ 13 November 1978,¹⁵² 20-21 November 1979,¹⁵³ 9 October 1981,¹⁵⁴ 13 September 1982,¹⁵⁵ 17 October 1983,¹⁵⁶ 27 September 1984,¹⁵⁷ and 21 October 1985.¹⁵⁸

62. It does not appear that Dr Ibbotson contributed to the Glasgow Symposium on *“Unresolved problems in Haemophilia”* in 1980,¹⁵⁹ or the Manchester Symposium on *“Current Topics in Haemophilia”* in 1982.¹⁶⁰

¹⁴⁸ WITN4678001 para 20

¹⁴⁹ WITN4678001 para 31

¹⁵⁰ PRSE0002268

¹⁵¹ PRSE0001002

¹⁵² HSOC0010549

¹⁵³ CBLA0001028

¹⁵⁴ CBLA0001464

¹⁵⁵ CBLA0001619

¹⁵⁶ PRSE0004440

¹⁵⁷ PRSE0003659

¹⁵⁸ PRSE0001638

¹⁵⁹ RLIT0001242

¹⁶⁰ DHSC0002221_003

Knowledge of risk of AIDS and response to risk

63. In relation to knowledge of risk of AIDS, Dr Ibbotson stated:¹⁶¹

“Initially there was no indication that blood products could cause the transmission of HIV. Over time it became clear that it was a serious developing problem. Unfortunately it was apparent that stopping the use of blood and blood products could not happen.”

64. He added, in relation to timing:¹⁶²

“During various meetings it became apparent that there was an association between blood products and HIV in approximately 1983.”

65. In response to the knowledge of risk, Dr Ibbotson stated:¹⁶³

“All patients were treated with heat treated blood products. Fortunately, at North Staffs we were lucky in that regard, even though heat treated BPL Factor VIII was very limited and the demands of Birmingham Children’s Hospital had to be met.”

66. Dr Ibbotson stated that *“To my recollection all patients were switched to heat treated products as soon as available”*.¹⁶⁴

67. Following the UKHCDO meeting on 17 October 1983, Dr Ibbotson agreed with the decision that patients should not be encouraged to go over to cryoprecipitate for home therapy but should continue to receive NHS or commercial concentrates.¹⁶⁵ He stated

¹⁶¹ WITN4678001 para 23

¹⁶² WITN4678001 para 24

¹⁶³ WITN4678001 para 25

¹⁶⁴ WITN4678001 para 26

¹⁶⁵ WITN4678001 para 32(e)

that they had no problems in securing factor VIII and that he was able to obtain unlimited amounts of cryoprecipitate.¹⁶⁶ Looking back now, Dr Ibbotson stated that he would not change any of his actions.¹⁶⁷

Testing patients for HTLVIII and informing them of diagnosis

68. Dr Ibbotson stated that he first discussed AIDS/HTLVIII with patients “*As soon as [the] problem with Factor VIII concentrate became available*”.¹⁶⁸ When it came to pre-test and post-test counselling, Dr Ibbotson stated that “*A full discussion was undertaken prior to screening and post screening in out patients*”.¹⁶⁹ Patients who had been, or might have been, infected with HIV were told in person.¹⁷⁰ Dr Ibbotson stated that “*the dire prognosis was known to those who were positive from the publicity surrounding HIV*” and that it was “*left to their discretion who they told*”.¹⁷¹ Dr Ibbotson stated that “*All partners were offered tests when necessary*”.¹⁷²

69. An Inquiry witness has given evidence about- treatment he received at Birmingham Children’s Hospital and North Staffordshire (Stoke-on-Trent). He has provided a written statement dated 14 November 2018¹⁷³ and gave oral evidence to the Inquiry on 12 June 2019.¹⁷⁴ He contracted HIV from blood products used to treat severe haemophilia A. Although he tested positive for HIV at Birmingham, he was not aware of his infection with HIV from blood products until he transferred to Stoke-on-Trent in 1986. He explained how he was told of his infection:¹⁷⁵

“21. My first appointment at Staffordshire North Infirmary was on Monday 1 September 1986. I went to the appointment with my mother. We sat in the waiting room and were called into Dr Robert Ibbotson’s office. The door

¹⁶⁶ WITN4678001 para 32(c)-(d)

¹⁶⁷ WITN4678001 para 34

¹⁶⁸ WITN4678001 para 37

¹⁶⁹ WITN4678001 para 39

¹⁷⁰ WITN4678001 para 40

¹⁷¹ WITN4678001 para 41

¹⁷² WITN4678001 para 42

¹⁷³ WITN0012001

¹⁷⁴ INQY1000018

¹⁷⁵ WITN0012001 paras 21-23

remained open allowing people behind me to hear the conversation. The doctor said, "Good morning, I see you are HIV positive." Just like that. I looked at him, looked back at my mum and said "well that's life".

22. Dr Ibbotson said, "that is your life for the next two years". He said I have two years left to live. That is when it hit me and I went into a state of disbelief after which I cannot remember a single word he said to me.

23. Upon reflection I struggle to understand why a health care professional would announce my condition in the hearing of other patients. This was confidential information and I find it quite hurtful that other people were made aware of my condition. I also believe his bedside manner to be lacking in empathy and sympathy."

Numbers infected with HIV

70. According to provisional data received by the Inquiry from UKHCDO, it appears that 6 patients were infected with HIV at Stoke Hospital: 1 patient in 1981 and 5 patients in 1985.¹⁷⁶

71. Dr Ibbotson stated that *"no serum was retained"*.¹⁷⁷

Testing for HCV

72. As far as Dr Ibbotson could recall, *"no patient had clinical non A or non B Hepatitis"*.

¹⁷⁸ He could not recall how many patients were infected with hepatitis C.¹⁷⁹ He stated that *"As soon as this test became available for Hep C at the North Staffs lab all patients were informed by me in person of their Hep C status"*.¹⁸⁰ Dr Ibbotson could

¹⁷⁶ INQY0000250

¹⁷⁷ WITN4678001 para 44

¹⁷⁸ WITN4678001 para 50

¹⁷⁹ WITN4678001 para 54

¹⁸⁰ WITN4678001 para 51

not recall the date that testing began.¹⁸¹ He stated that *“All patients at the Centre were tested for HCV”,*¹⁸² and that *“All information in my possession was discussed with the patient”.*¹⁸³ Dr Ibbotson also stated that as far as he could recall, *“there would have been no delays in indicating results”.*¹⁸⁴ He also stated:¹⁸⁵

“All patients were tested for Hep C and HIV when testing became available. The patients were all aware of the significance of the tests. No record of consent was recorded as the request for blood testing was written in front of the patient. No one was tested without being told.”

73. An anonymous witness stated that she was not informed that she had contracted hepatitis C until 1992 despite repeatedly visiting the GP as she was experiencing symptoms.¹⁸⁶ She described learning of her HCV diagnosis as follows:¹⁸⁷

“23. In August 1992, I had a regular appointment with Dr Ibbotson. I was still experiencing extreme fatigue. I explained the symptoms to him and he said, “oh, we better take some tests then.” He took blood tests on that day and I did not have to wait long for the results.

24. I went back to see Dr Ibbotson on 7 September 1992 for the results and he said, “I’m glad to tell you, you don’t have HIV, you don’t have Hepatitis B but I’m sorry to tell you, you have Hepatitis C.” I was told very bluntly. My husband was not with me at the appointment because Dr Ibbotson did not indicate that I should be expecting bad news.

25. I asked Dr Ibbotson what having Hepatitis C meant and he said, “oh you’re another one that’s going to sue me.” He said this in a jokey way but

¹⁸¹ WITN4678001 para 51

¹⁸² WITN4678001 para 52

¹⁸³ WITN4678001 para 53

¹⁸⁴ WITN4678001 para 55

¹⁸⁵ WITN4678001 para 57

¹⁸⁶ WITN3160001 para 22

¹⁸⁷ WITN3160001 paras 23-26

given the topic of conversation, I did not think that was appropriate. I had gotten to know Dr Ibbotson well over the years he was treating me and he did have a jokey manner. However, I still do not think the way in which I was told I had Hepatitis C was appropriate.

26. I asked for some more information about Hepatitis C and he said he did not know much about it. I was told that the virus was attacking my liver and then when my liver was destroyed, there would be nothing more they could do. I was told that I could not have a liver transplant because I was already too old. He did ask if I had any questions, but I felt so shocked I only asked a few.

27. I was in a total state of shock. I went home and told my husband that I had contracted Hepatitis C. I told my husband that I did not have very much information. I recall at some point the Hepatitis nurse gave me a booklet on Hepatitis C but that was at least a few years after this. In terms of the risk of transmitting Hepatitis C, we had to find out information ourselves and I was not told anything by a doctor. If I did not have a husband that was so amazing, then I do not know what I would have done.”

74. In relation to testing for hepatitis C and HIV, the witness stated:¹⁸⁸

“I was not aware that I [would] be tested for Hepatitis C when I went for blood tests in 1992. I did not know Hepatitis C was a possibility. According to the Report, Dr Ibbotson completed a HIV test in 1985 and it was negative. I cannot recall being told about the results of the HIV test in 1985; I believe I was told in 1992.”

Treatment arrangements for HIV and HCV patients

¹⁸⁸ WITN3160001 para 32

75. Dr Ibbotson explained that for the care and treatment of patients with HIV/AIDS, patients were managed locally but offered a referral to Birmingham.¹⁸⁹ He stated that all hepatitis C patients were referral to Queen Elizabeth Haemophiliac Unit.¹⁹⁰

76. The witness described her treatment as follows:¹⁹¹

“I have mainly needed treatment for my Hepatitis C. I have routine appointments once every 12 months to review and check my clotting level. Knowing my clotting level has been useful in case I ever needed an operation, although thankfully this has not been necessary so far.”

77. She also stated that she received all her treatment at Stoke and received no counselling.¹⁹²

“I received all of my medical treatment at the RSH [Royal Stoke Hospital]. I was never offered any counselling in respect of either my diagnosis or the treatment for Hepatitis C. I would have accepted it had it been offered.”

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September 2021

¹⁸⁹ WITN4678001 para 66(a)

¹⁹⁰ WITN4678001 para 69(a)

¹⁹¹ WITN3160001 para 9

¹⁹² WITN3160001 para 55