SMALLER HAEMOPHILIA CENTRES PRESENTATION

DUNDEE

The Directors

1. Unlike other Scottish haemophilia centres, haemophilia care for those living in and around Dundee was not organised under a formal haemophilia centre during the 1970s and 1980s.

2. From 1968 to 1972 adult haemophiliacs in Dundee were under the care of Professor R. B. Hunter at the Maryfield Hospital, Dundee.[1] From 1972 adult haemophiliacs in Dundee were under the care of Dr G. R. Tudhope.[2] From 1975 Dr Tudhope was based at Ward 5/6 at Ninewells Hospital, Dundee ("Ninewells").[3]

3. From the late 1970s Dr Sydney G. F. Wilson was in charge of paediatric patients based at Ward 30 of the Ninewells Hospital.[4] During the AIDS crisis Dr Wilson and Dr Tudhope held joint clinics for testing paediatric patients.[5] However, Dr Cachia has told the Inquiry that while '*a nominated consultant paediatrician did provide continuous care for boys with haemophilia ... there was little planned networking or linkage between the paediatric service and haematology department.*'[6]

4. Dr Tudhope retired in around 1986 and Dr Andrew Heppleston, Consultant Haematologist, was given the title of Director.[7] He was in charge of the care of adult patients with haemophilia until 1991.[8] Dr Heppleston has been described by his successor in the following terms: '*he was not a specialist in haemophilia care*

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[1] OXUH0003635
[2] Dr Tudhope had a wide range of medical interests beyond haemophilia. He was a member of the British Pharmacopeia Commission during the 1970s retiring from that position in 1979.
[3] PAHO0000001. He was previously based at the Therapeutics Unit of the Maryfield Hospital, Dundee: OXUH0003712_002
[4] HCDO0000138_007
[5] WITN2192006
[6] §8.1 of WITN4028001
[7] PRSE0001081
[8] He was a co-author alongside Bennet B, Dawson A A, Gibson B S, Lowe G D O, Ludlam L A L, Mayne E E and Taylor T in the 1993 'Study of viral safety of Scottish National Blood Transfusion Service Factor VIII/IX Concentrate, *Transfusion Medicine*, 3, 295- 298.

and had a very heavy clinical load looking after patients with haematological malignancies.'[9]

5. That successor, Dr Philip Cachia, was appointed Director from April 1992[10] to 2004. He formally established the Tayside Haemophilia Centre in 1992. He has provided a witness statement to the Inquiry.[11]

6. Dr Rosalie Wilkie replaced Dr Wilson as the lead consultant in charge of paediatric haemophilia care. Dr Margaret Peebles later replaced Dr Wilkie in the early 2000s.

7. Dr Ron Kerr became Acting/Locum Consultant Haematologist and Haemophilia Director from December 2003 to April 2004 and then from September 2004 to March 2005. In March 2004 Dr Kerr became Consultant Haematologist and Haemophilia Director of the Centre.[12] Dr Kerr has provided a witness statement to the Inquiry.[13]

Other staff members

8. During the 1970s and 1980s junior clinicians frequently deputised for Dr Tudhope at SNBTS and UKHCDO meetings. For example, Dr Douglas Shaw[14] was appointed as Senior Registrar in 1973 and attended the SNBTS Directors and Haemophilia Directors meeting held on 8 May 1975 on behalf of Dr Tudhope to discuss factor VIII and its supply.[15] He also attended the 13 November 1978 UKHCDO meeting in Oxford[16] and the 30 September 1980 meeting of the UKHCDO held at Glasgow.[17]

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[9] §8.1 of WITN4028001
[10] SBTS0000260_033
[11] WITN4028001
[12] Known as NHS Tayside.
[13] WITN4749001
[14] A visiting patient to Dundee wrote in the Northumbrian branch of the Haemophilia Society's Bulletin that Dr Shaw had 300 haemophiliac patients under his care in 1975: HSOC0021654. However, other documents do not suggest that Dr Shaw was in charge of haemophiliac patients or that there were 300 patients in 1975.
[15] CBLA0000275
[16] HSOC0010549
[17] PRSE0003946

9. Dr Alastair Todd represented Dr Tudhope at the 20-21 November 1979 UKHCDO meeting held in Oxford.[18] Dr A. Sharp attended a number of meetings on behalf of Dr Tudhope in the early to mid 1980s.[19]

10. From 1995 to June 2018 Mrs June Ward was the Centre's specialist haemophilia nurse. Mrs Ward gave evidence at Penrose and has provided a statement to the Inquiry.[20]

11. In June 2018 to the present, Mr Lee Newman was the Centre's specialist haemophilia nurse.[21]

12. From around 1997 Dr Helen Murrie was employed as a clinical assistant. This post was established to see patients alongside the specialist haemophilia nurse. When she returned to her GP work, Dr Ron Kerr did not replace the post because he was able to undertake those clinics himself in addition to the specialist nurse working independently.[22]

13. Dr J. F. Dillon, Consultant Gastroenterologist, although not part of the Centre, has treated Dundee haemophiliacs infected with HCV since the late 1990s.

The Centre

14. The Centre was not formally established until 1992 by Dr Philip Cachia. When he established the Centre there were around 25 patients with severe haemophilia. This number of patients meant that the Centre could not become a UKHCDO comprehensive care centre.[23] The Centre therefore had a formal link with Edinburgh for advice '*but without having to transfer patients with haemophilia to Edinburgh for clinical care.*'[24]

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[18] BPLL0007384
[19] Such as the 13 September 1982 UKHCDO meeting: DHSC0006161; the 7 March 1985 meeting of the Directors of SNBTS and Centre Directors: SBTS0000829; the 23 September 1985 meeting of Scottish Haemophilia Centre Directors: MACK0001055_001
[20] WITN4056001
[21] §7 of WITN4749001
[22] §7 of WITN4749001
[23] The UKHCDO requirement was for a minimum of 30 patients with severe haemophilia.
[24] §9.2 of WITN4028001

15. Upon Dr Cachia's arrival there was no specific Centre or dedicated location for haemophilia care. Patients were seen on the general haematology ward or day unit. The available haemophilia care:

> '*predominantly consisted of a 'crisis intervention service' providing emergency and inpatient care in the event of acute bleeding or other medical problems. Medical staff in the Haematology department provided some pro-active advice and routine assessment of haemophilia and its complications on an opportunistic basis but there was no managed or organised system of routine or prospective review of patients with clotting disorders in terms of their general health, joint disease or any of the complications of haemophilia or its treatment.*'[25]

16. Adult patients on home therapy obtained supplies by contacting a technician in the SNBTS laboratory '*and were issued with the required product without regular medical supervision or formal review of their treatment'*.[26] He states:

> '*There were no formal liaisons between the Haematology department and key specialist services essential for the provision of comprehensive Haemophilia care including dentistry, the HIV service, hepatology, orthopaedic surgery, physiotherapy, social work or psychological counselling services. The Haematology coagulation laboratory provided a comprehensive coagulation service including factor and inhibitor assays required to monitor Haemophilia care although not every on call biomedical scientist was able to perform these assays as an emergency, out of hours procedure.*'[27]

17. Dr Cachia has told the Inquiry that in 1992 when he arrived the haematology department '*did not keep any records of factor concentrate stocks, batch numbers, issues to patients or home treatment use. Details of factor concentrates given in Ninewells Hospital were inconsistently recorded in the relevant patient's medical records. This situation was in part due to the underdeveloped haemophilia service*' and due to '*the unusual circumstance of a regional SNBTS service (situated in the main hospital) and providing services of both a regional transfusion centre (blood collection, donor management etc) and the local hospital transfusion and cross-matching services. To my knowledge Dundee and*

[25] §8.1 of WITN4028001
[26] §8.1 of WITN4028001
[27] §85.1 of WITN4028001

Aberdeen were unique in that the regional SNBTS service rather than the Haematology service delivered transfusion services to clinical users.' [28]

18. Upon his arrival Dr Cachia initiated joint replacement surgery for haemophiliacs at Ninewells rather than sending these patients to Glasgow as was previously the case.[29] In his statement to the Penrose Inquiry he describes finding on his arrival a backlog of arthropathy of around 15-20 knee and hip joint replacements *'that were clinical priorities on the basis of severe arthritic pain.'*[30]

19. June Ward, specialist haemophilia nurse, has told the Inquiry that there was '*no standalone social worker*' at the Centre.[31] In the late 1990s there was a designated social worker for haematology and patients could be referred to her. However, this service was later cut and therefore patients had to be referred to the general social work department at the hospital.[32] The Centre also made use of national Haemophilia Society social workers.[33]

20. The Centre is currently a designated Haemophilia Treatment Centre.[34] Dr Kerr states that due to its proximity to Dundee, a university teaching hospital, the Centre has '*always provided a spectrum of clinical activities similar to those provided by a Comprehensive Care Centre*' during his time working there.[35] The relationship with Edinburgh CCC relates to stock control and monitoring of factor concentrate use while all urgent and review appointments, surgery, and management of conditions like HCV take place at the Centre.[36]

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[28] §85.1 of WITN4028001
[29] SBTS0000343_034
[30] §3.9 of PRSE0003777
[31] §30 of WITN4056001
[32] §30 of WITN4056001
[33] §30 of WITN4056001
[34] In 2020 there were 541 patients registered at Dundee HTC. 46 with Haemophilia A, 10 with Haemophilia B, 189 with von Willebrand's disease and 296 with other congenital bleeding disorders: §9 of WITN4749001
[35] §6 of WITN4749001
[36] §6 of WITN4749001

Blood Transfusion Service

21. From 1954 to 1981 Dr Charles Cameron was the Director of the East of Scotland Blood Transfusion Service ("ESBTS"). In 1974 the ESBTS blood laboratory moved to the newly opened Ninewells Hospital.[37] Dr Ewa Brookes became the BTS Director in 1981.[38]

22. As with other Scottish Centres, there were close links between the Centre and its local transfusion service. For example, Dr Brookes represented Dr Tudhope at the Haemophilia Centre Directors' 14th meeting on 17 October 1983.[39] Dr Cachia describes '*a close working relationship with the Director and staff of the regional SNBTS service based in Ninewells Hospital.*' The relationship '*centred around factor concentrate stocks and usage, individual patient usage, and keeping SNBTS informed of any changes in factor concentrate usage including increased requirements to cover elective orthopaedic surgery.*'[40]

23. As at May 1983 the ESBTS was noted to have collected 33,000 donations per annum, 60% of which were processed in the ESBTS' blood products laboratory.[41] Part of the ESBTS' role was to give '*advice on the appropriate use of blood and the various blood products available, including platelets, factor VIII concentrate and immunoglobulins.*' There was also a Hepatitis Laboratory that tested '*all donor samples*' as well as the region's antenatal samples, '*enabling clinicians to identify mothers who are carriers of Hepatitis B Antigen and offer treatment for the infants.*'[42] The ESBTS Centre was '*intermittently*' required to provide rotational training of the registrars and senior registrars from the haematology department of the Ninewells Hospital.[43] After Dr Brookes raised concerns about

[37] SBTS0000051_041
[38] She attended her first meeting of the Directors of SNBTS and Centre Directors on 21 January 1983: PRSE0001736. She was a co-author with R. I. G. Cuthbert, C.A Ludlam and D. B. L. McClelland on the Efficacy of Heat Treatment of Factor VIII Concentrate: STHB0000159
[39] PRSE0004440
[40] §81.1 of WITN4028001
[41] SBTS0000236_015
[42] SBTS0000236_015
[43] SBTS0000236_015

inadequate staffing levels, Dr Cash supported her request for a second consultant for the ESBTS as well as additional funding for associate positions.[44]

24. On 23 August 1983 Dr Brookes wrote to Dr Cash, the national director of SNBTS, regarding her attendance at a meeting of the Working Party on Selection of Donors / Notes for Transfusion. At that meeting there was a discussion about donor sessions at prisoners and borstals. She reported:

> '*You asked me to discuss this with my colleagues. In fact, no discussion was necessary since as far as England and Wales are concerned these sessions have already been stopped. It is now left to the Scottish regions to decide whether they will do the same.*'[45]

25. After this meeting the SNBTS National Director asked Dr Brookes '*to ring round*' to informally check the position with other Directors.[46] She contacted 12 out of 14 of the Directors. Out of the 12, 11 were not holding prison donor sessions.[47] Dr Brookes provided a witness statement to the Penrose Inquiry where she explained that her concerns about the use of blood from prisons was based on her experience in the late 1970s working as a Consultant in the South London Regional Transfusion Service where she attended donor sessions in prisons.[48] In the first part of 1983 Dr Brookes asked the Organising Secretary to '*phase out prison and young offenders sessions over the coming year.*'[49]

26. At the ESBTS Dr Brookes held stored samples from those who had donated blood stretching back to September 1983.[50] This enabled her to pass onto the National Blood Transfusion Service details of likely HIV seroconversions of blood donors. It is unclear if donors' consent for this storage was obtained.

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[44] SBTS0000236_013
[45] PRSE0002981. The Medical Inspectorate report of 25 March 1982 had already stated that there could not be continued support for collection of blood from such places as prisons and borstals: ARCH0002306_002
[46] Page 14, PRSE0001873
[47] Page 14, PRSE0001873
[48] Page 3, PRSE0001873
[49] Page 6, PRSE0001873
[50] NHBT0019494

27. Throughout the 1980s it was repeatedly recognised that the facilities at the ESBTS Centre needed improvement. In 1982 it was acknowledged by the SNBTS that the ESBTS Centre required new accommodation. The plan was for extra accommodation and it was hoped that existing vacant accommodation at Ninewells complex would be realised. The plan was for new accommodation by June 1984 after the Medicines Inspectorate visit.[51] On 23 May 1984 the Scottish Health Service agreed to the development of an improved blood products laboratory in the previously unallocated space on level 8 of the Ninewells Hospital and the development of separate changing facilities for hepatitis testing staff.[52] The plan was for completion in 1987 / 1988. However, that timeline was not met and a Medicines Inspection in October 1988 found that the ESBTS' blood products laboratory at Dundee remained inadequate. Further redevelopments were planned in the early 1990s.

Facilities and staffing in 1970s and 1980s

28. During the 1970s and 1980s there was no separate centre for haemophiliacs. They received their care on the general haematology ward or day unit.[53]

29. In 1979 a new group of the Haemophilia Society was formed in Dundee and was known as the Tayside Group. This group was involved in fundraising for haemophilia care at Dundee.[54] In August 1979 it was noted that the newly formed Tayside Group had requested funding for equipment (£500) and to establish a fund for doctors at Ninewells Hospital to travel to haemophilia conferences and/or for patients to travel for treatment or consultation at other centres (£1,000).[55] The funds for equipment were agreed but the proposed fund divided views on the Society's Medical Advisory Panel and the Council.[56] These views were conveyed back to the Tayside Group and ultimately it was not agreed for the money to be

[51] SCGV0000270_032
[52] SBTS0000138_029. This was agreed for a period of 10 years and then to be subject to further review.
[53] §3.3 of PRSE0003777
[54] This was announced in the 29th Edition of the Society's Bulletin in the following terms: '*The Group will work in close liaison with our Scottish Group and has already raised over £2,000, a large proportion of which will be used to support the work of the Haemophilia Centre at Ninewells Hospital, Dundee.*': HSOC0022871
[55] HSOC0019919_005
[56] HSOC0019919_007

used in this way. The issue was that Ninewells was not a research centre and therefore it was '*difficult for the Group to know how to put the money to the best possible use*'.[57] Agreement was reached for this money to be of general use to Ninewells and/or the Tayside Group '*for any appropriate purpose which may arise.*'[58] A further sum of £1,883.80 was provided to Ninewells for additional equipment.[59]

30. However, a July 1983 request by the Tayside Group to support Dr Tudhope with expenses to attend the October UKHCDO meeting was rejected.[60] This decision was then overturned in August 1983, albeit with the Society stressing the unique nature of this situation.[61] According to the minutes, Dr Brookes attended the UKHCDO meeting as Dr Tudhope's representative in any event.[62]

31. In October 1990 the Tayside Group made a successful application '*to fund a replacement centrifuge for factor assays at the Dundee Centre.*'[63]

Numbers of patients registered and numbers of patients treated

32. The UKHCDO annual return for 1976 states that 12 haemophilia A and six haemophilia B patients were treated by Dr Tudhope that year.[64] There were no deaths in that year. The treatment given was cryoprecipitate, NHS factor VIII and factor XI.

33. The UKHCDO annual return for 1977 states that 10 haemophilia A and six haemophilia B patients were treated by Dr Tudhope that year.[65] There were no deaths in that year. The treatment given was cryoprecipitate, Edinburgh NHS

[57] HSOC0019918_024
[58] SBTS0000236_013
[59] Specifically, for a Photometer 4010 and a Precitherm PFV Waterbath and Perspex Rack: HSOC0019919_030
[60] HSOC0029476_026
[61] HSOC0029476_027
[62] PRSE0004440
[63] HSOC0010398
[64] HCDO0002444
[65] HCDO0002445

factor VIII and factor XI. There were two patients with von Willebrand's, who were treated with cryoprecipitate and NHS factor VIII.

34. The UKHCDO annual return for 1978 states that 11 haemophilia A (including one with factor VIII antibodies) and six haemophilia B patients were treated by Dr Tudhope that year.[66] There were no deaths in that year. The treatment given was cryoprecipitate, Edinburgh NHS factor VIII, factor XI and plasma. The patient with the inhibitor was treated with 12 bottles of cryoprecipitate. There were two patients with von Willebrand's, who were treated with cryoprecipitate.

35. The UKHCDO annual return for 1979 states that 9 haemophilia A and five haemophilia B patients were treated by Dr Tudhope that year.[67] Despite the reduction in the numbers from the previous year, there were no deaths in that year. The treatment given was cryoprecipitate, Edinburgh NHS factor VIII, factor XI and plasma. There were two patients with von Willebrand's, who were treated with cryoprecipitate and plasma.

36. The UKHCDO annual return for 1980 states that 9 haemophilia A and three patients with von Willebrand's were treated by Dr Tudhope that year.[68] The treatment given was cryoprecipitate, NHS factor VIII and IX.

37. The UKHCDO annual return for 1981 shows that around 19 haemophilia A and 9 haemophilia B patients were treated by Dr Tudhope that year.[69] The treatment given was cryoprecipitate, NHS factor VIII and IX.

38. The UKHCDO annual return for 1982 shows that around 20[70] haemophilia A and 10 haemophilia B patients were treated by Dr Tudhope that year.[71] There were four patients with von Willebrand's. One patient with inhibitors was given porcine factor VIII in the form of 35 bottles of Speywood Hyate C. Other than this

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[66] HCDO0002446
[67] HCDO0002447
[68] HCDO0002448
[69] HCDO0002449
[70] After one patient had his diagnosis changed from von Willebrand's to haemophilia A.
[71] HCDO0002450

commercial product, the products used were NHS factor products and cryoprecipitate.

39. The UKHCDO annual return for 1983 shows that 14 haemophilia A, six patients with haemophilia B and two patients with von Willebrand's were treated that year.[72] Only Scottish factor products and cryoprecipitate were used.

40. The UKHCDO annual return for 1984 shows that 10 haemophilia A and 4 patients with haemophilia B were treated that year.[73] Only Scottish factor products and cryoprecipitate were used.

41. The UKHCDO annual return for 1985 shows that 12 haemophilia A and seven patients with haemophilia B were treated that year.[74] Only Scottish factor products were given, with no cryoprecipitate in that year.

42. The UKHCDO annual return for 1986 shows that 14 haemophilia A and four patients with haemophilia B were treated that year.[75] Only Scottish factor products and cryoprecipitate were used.

43. The UKHCDO annual return for 1987 shows that 14 haemophilia A and five patients with haemophilia B and 3 patients with von Willebrands were treated that year by Dr Heppleston.[76] Only Scottish factor products and cryoprecipitate were used.

44. The UKHCDO annual return for 1988 shows that 16 haemophilia A and four patients with haemophilia B were treated that year by Dr Heppleston.[77] Only Scottish factor products were given, with no cryoprecipitate in that year.

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[72] HCDO0002451
[73] HCDO0002452
[74] HCDO0002453
[75] HCDO0002454
[76] HCDO0002455
[77] HCDO0002456

Treatment policies and blood product usage

45. Dr Cachia informed the Penrose Inquiry that only SNBTS blood products were used at Ninewells. This is borne out by the UKHCDO annual returns set out in the previous section.

46. Dr Cachia has described to this Inquiry that the selection, purchase and use of factor concentrates was managed on '*an all Scotland basis by the Scotland and NI Haemophilia Directors Group which worked closely with the Coagulation Factor Working Party (which consisted of Haemophilia Directors, SNBTS and the Protein Fractionation Centre (PFC) representatives and Scottish Executive Medical Directorate representation*.'[78]

47. The Penrose Inquiry concluded that the preference at Dundee, like that of Aberdeen and Inverness, '*point[ed] clearly towards a preference for NHS products*' and that the use of imported commercial concentrates was '*very infrequent throughout the material time*'.[79] According to documentation produced by Speywood, concerning 1981-1984, 23,400 units of Hyate:C were shipped to Ninewells in 1982.[80] Analysing the annual return for that year, this was for a patient who had developed an inhibitor.

48. The Penrose Inquiry found that Dundee used '*cryoprecipitate in 1981, as the centre had in previous years. In that year and later, however, it accounted for only a small percentage of total therapy which, as noted above, was based on almost exclusive use of PFC Factor VIII.*[81]

49. In the same year, on 7 September 1981, Dr Brookes, the newly appointed Director of the ESBTS, wrote to Mr John Watt, Director of the PFC, requesting further supplies of factor VIII concentrate. She stated:

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[78] §10.2 of WITN4028001
[79] §12.24, chapter 12 of PRSE0007002
[80] IPSN0000036_012
[81] §12.157 and see table 12.1 of PRSE0007002

'*Our occasional haemophiliacs have all required concentrate at roughly the same time which depleted our stocks and currently a 61 year old haemophiliac with an inhibitor is an in-patient with haematuria. It was his presence that made me think we need some additional concentrate at the Centre.*'[82]

50. There is a handwritten note at the bottom of this request to Bill (presumably Bill Cash) from John (presumably John Watt) that states that Dr Brookes '*should have brought this [factor VIII] commercially!*'[83]

51. In relation to home treatment, Dr Brookes, in a letter dated 31 January 1983 to John Watt, wrote that over the last two years there had been '*several patients who ha[d] been established on Home Treatment*'.[84] From at least 1984 it was the policy of the ESBTS to ask patients on home treatment to record the batch numbers of the vials they used.[85] June Ward, haemophilia nurse, describes that there was '*little or no organised home treatment or prophylaxis for children prior to 1995.*'[86]

52. As with other Scottish centres, patients at Dundee were moved onto heat-treated products and then high purity products. High purity SNBTS Factor VIII concentrate (Liberate) was introduced in NHS Scotland in the early 1990s to replace intermediate purity Factor VIII (Z8).[87] One paediatric patient's medical records from August 1992 show the change in product: '*Scottish Blood Transfusion are going to be changing over to highly purified factor VIII in September and this will require all the ch*ildren *to be changed over at that time. Because it as yet only has a provisional licence it will require that those who are being changed over should be monitored carefully and I have explained that to the parents.*'[88]

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[82] SBTS0000306_087
[83] SBTS0000306_087
[84] SBTS0000315_038
[85] SBTS0000319_047
[86] §8 of WITN4056001
[87] §22.2 of WITN4056001
[88] WITN2192004

Knowledge of risk of hepatitis and response to risk

53. There is no specific documentary evidence available about Dr Tudhope's knowledge of, and response to, the risk of hepatitis.

54. Dr Tudhope attended the 5 April 1971 meeting of the UKHCDO at the Churchill Hospital, Oxford.[89] At that meeting Dr Biggs provided a short summary of her report on the incidence of jaundice and inhibitors in haemophiliac and Christmas disease patients treated during 1969. Directors were asked about their figures of Australian antigen and antibody testing.[90]

55. Dr Tudhope attended the 18 September 1975 meeting of Haemophilia Centre Directors held in Glasgow, where Dr Biggs presented her paper on the study of jaundice and factor VIII antibodies. At the same meeting Professor Ingram highlighted that NHS factor VIII was '*derived from pools of 500-750 donations whereas the commercial factor VIII was often derived from pools of 2,000 to 6,000 litres of plasma and that the probability of including an infected donation was greater with commercial factor VIII.*'[91]

56. Dr Tudhope also attended the UKHCDO meeting on 13 January 1977 where Dr Craske presented a written report on his study of hepatitis in haemophiliac patients.[92]

57. Dr Tudhope attended the UKHCDO meeting on 9 October 1981.[93] At this meeting Dr Craske presented a report on behalf of the Working Party on Hepatitis and presented his findings of a three-year retrospective study. One of the recommendations made by Dr Craske was that batch numbers of materials received by patients who developed hepatitis should continue to be collected.[94]

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[89] HCDO0001014
[90] Dr Tudhope did not attend the 27 October 1972 meeting and he sent Dr Todd as his representative for the 31 January 1974 and the 20-21 November 1979 UKHCDO meeting. It may be reasonable to assume that he would have received the minutes of the meetings.
[91] OXUH0003735
[92] PRSE0002268. He did not attend the next UKHCDO meeting on 24 October 1977.
[93] CBLA0001464
[94] Page 20 of CBLA0001464

The possible commercial production of hepatitis-free factor IX concentrate was also discussed.[95]

Knowledge of risk of AIDS and response to risk

58. There is no specific documentary evidence available about Dr Tudhope's knowledge of and response to AIDS.

59. Dr Tudhope did not attend the meeting of the Directors of SNBTS and the Centre Directors on 21 January 1983 where Dr Cash drew attention to recent articles in the United States and in *the Observer* and *The Lancet* about AIDS.[96]

60. According to the Penrose report, in March 1983 Dr Peter Foster of the PFC gave a series of presentations to haemophilia clinicians and haematologists in Edinburgh and in Dundee on the issue of AIDS.[97]

61. Dr Heppleston attended the 27 September 1984 UKHCDO meeting where Dr Craske referred the Directors to his report on AIDS and outlined the relevant literature.[98]

62. Dr Tudhope did not attend the 7 March 1985 meeting of Scottish Haemophilia Centre Directors and sent Dr A. Sharp in his place .[99] At that meeting Dr Perry informed the Directors that there were plans for new screening tests for HTLV III antibodies to be evaluated on a UK basis: '*there was deep concern about reports indicating a high proportion of false positives*' in the trials carried out in the United States.

63. Dr A. Sharp also attended the 23 September 1985 meeting of Scottish Haemophilia Centre Directors meeting on behalf of Dr Tudhope.[100] At the September meeting it was stated that '*most*' Scottish haemophiliacs had

[95] Page 20 of CBLA0001464
[96] PRSE0001736
[97] P§11.82 of PRSE0007002
[98] PRSE0003659
[99] SBTS0000829
[100] MACK0001055_001

undergone anti-HTLV III testing. The possibility of sexual and family transmission of HTLV III was discussed and it was noted that '*no contact living in Scotland was known to be anti-HTLV III positive.*'[101] Dr Tudhope also did not attend the 21 October 1985 UKHCDO meeting and again sent Dr A. Sharp in his place.[102] At this meeting Dr Craske presented his report and described an '*upward curve*' of AIDS/ARC cases in the UK. Issues such as testing, further studies and counselling were discussed.

Arrangements for testing patients for HTLV III and informing them of their diagnosis

64. The data collected by the Penrose Inquiry suggests there were 24 tests for HIV at Dundee between 1985 and 1987.[103]

65. The medical records of one patient state that he attended '*a special clinic for haemophiliacs on 11th January'* 1985 which was '*arranged along with Dr George Tudhope so that the problem of AIDS could be explained.*' The patient was five years old at this time of the clinic. His blood was taken for testing and the sample was sent to Edinburgh '*along with others obtained at the same time from other haemophiliacs.*'[104] In oral evidence to the Inquiry this witness stated that his parents have no recollection of attending that clinic or receiving the results of that test. He stated:

> '*… I've spoken to my Mum and my Dad about it. They have no recollection at all of this special clinic. They believe if this did happen, it would have been dressed as a standard haemophilia check-up, but they have no recollection of it whatsoever. As a parent myself, I think I was asked to come in and have my child tested for AIDS I would remember it, and my parents have no recollection of this whatsoever.*'[105]

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[101] MACK0001055_001
[102] PRSE0001638
[103] PRSE0007002
[104] WITN2192006
[105] PRSE0007002

Numbers infected with HIV

66. The Penrose Inquiry, following information provided by Dr Ron Kerr, Director of the Centre from 2005 onwards, concluded that no haemophilia patients were considered to have been infected with HIV as a result of treatment at Dundee.[106]

67. This is consistent with the provisional data this Inquiry has received from the UKHCDO.[107]

68. In his written evidence to this Inquiry, Dr Kerr has stated that: '*no existing Dundee HTC patients (or to my knowledge previous and now deceased patients treatment in Tayside) had HIV or chronic Hepatitis B infection.*'[108]

HIV treatment

69. Although it appears that no haemophiliacs at Dundee were infected with HIV, Dr Cachia has told the Inquiry that during his time as Director (1992-2004) the Centre did care for a haemophiliac patient with HIV. That patient had been diagnosed with HIV at another centre and was already on antiviral treatment. His recollection is that the patient attended the local HIV clinic.[109] June Ward, haemophilia nurse who was appointed in 1995, recalls that there was one patient who had HIV '*who was looked after by the Edinburgh CC'* who died shortly after she commenced her post.[110]

HCV Testing

70. Dr Cachia has told the Inquiry that there were '*significant delays*' between the anonymous testing of stored sera in 1991 and '*informing patients at clinical review from 1992 onwards*'. [111] In 1992 when Dr Cachia arrived at Ninewells Dr Heppleston:

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[106] Page 75 of PRSE0005027
[107] INQY0000250
[108] §8 of WITN4749001
[109] §57.2 of WITN4056001
[110] §13 of WITN4056001
[111] §46.2 of WITN4028001

'*provided me with a box of file cards containing the name and details of all patients with inherited bleeding disorders who had attended and/or been registered with the department. Dr Heppleston also had a list of around 30 of these patients, whose stored serum had been tested for HCV antigen when the first test was introduced in 1991. From memory, around 25 of these patients had tested positive.*'[112]

71. Despite the existence of this list, it appears that patients had not been informed of their infections with HCV. Dr Cachia then had the stored serum analysed for HCV antigen with a commercial assay kit:

'*Following discussion with Dr Heppleston and Dr Urqhuart (consultant virologist in the Ninewells Department), I concluded that the samples had been analysed without any patient's consent. I do not know whether the patients had consented to having their serum samples stored.*'[113]

72. Dr Cachia has told the Inquiry that appointments were then arranged '*to undertake a full review of their bleeding disorder and management. Counselling for blood borne virus infections and treatment risks were a part of this process. For each of the patients who had been tested for HCV, I explained what had happened and requested their consent to repeat HCV testing on a fresh blood sample. Following a confirmatory HCV test, I met all the patients (and partners if appropriate) to explain the diagnosis and implications. From 1995, most consultations were undertaken by myself and June Ward, Haemophilia specialist nurse.*'[114]

73. The Inquiry has heard evidence that one infected haemophiliac was informed of his HCV infection '*in passing*' by his GP in 1993 when the patient was unaware he had been tested for HCV.[115]

74. Another patient, who has given both oral and written evidence to the Inquiry, states that at some point in 1994 '*when information was coming to light in the haemophiliac community*' his mother questioned his doctor about the possibility

[112] §42.1 of WITN4028001
[113] §42.3 of WITN4028001
[114] §42.4 of WITN4028001
[115] §6 of WITN2083001

he might have been exposed.[116] On 23 January 1995 he received a letter saying that he had been infected with HCV.[117] Dr Wilkie wrote:

'I have now gone through and looked at Graeme's results of his viral studies and in fact he does have a positive Hepatitis C antibody test which means that at some stage he has been exposed to Hepatitis C. Obviously there is a lot of press coverage about this at the moment and we obviously need to talk about this matter when he next comes to the clinic. If you wish to contact me before this please do.'[118]

75. He requested confirmation about when he was tested for HCV and was told that he had first tested positive in November 1992.[119] He is critical of the information provided upon diagnosis and thought at that time that HCV was '*a death sentence*' similar to AIDS.[120] No counselling was provided.[121]

76. Another witness, who received factor VIII in 1980 and in 1991, was diagnosed with HCV in May 1998 after being called to come to the haematology department at Ninewells.[122] He states he was not aware of ever being tested for HCV.[123] He believes he should have been diagnosed earlier as he was having blood taken every three months.[124]

77. An affected daughter describes that her father, who had haemophilia B, was given his diagnosis of HCV in or around 1995 when he attended a routine haemophilia appointment on his own. She states that he was surprised to see the consultant present and had just expected to have the appointment with haemophilia nurse, June Ward. The witness states that the news of his HCV was unexpected because he had never been told that he was being tested for HCV.[125]

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[116] §4 of WITN2192001
[117] WITN2192008
[118] WITN2192008
[119] §4 of WITN2192001 and WITN2192007
[120] §6 of WITN2192001. The relevant clinic letter, which sets out the advice given by Dr Wilkie is: WITN2192002
[121] §45 of WITN2192001
[122] §6 of WITN2290001
[123] §6 of WITN2290001
[124] §9 of WITN2290001
[125] §6 of WITN1181001

Numbers infected with HCV

78. According to the data gathered by the Penrose Inquiry, as at 2011, 21 living patients were estimated to have been exposed to HCV at the Centre. Sadly, 9 patients who had died as at 2011 were estimated to have been exposed to HCV.[126]

79. Dr Cachia has told the Inquiry that around 25 patients were infected with HCV at Ninewells.[127]

HCV treatment

80. Dr Kerr, in his witness statement to the Inquiry, has stated that together with Professor Dillon the Centre has now '*successfully treated all current patients with Hepatitis C infection following the development of novel direct acting antiviral therapies. Although earlier treatment with Interferon +/- Ribavirin was effective for some patients, this was not the case for many and it is very sad that several of our patients died of the complications of HCV prior to the availability of these subsequent highly effective novel therapies.*'[128]

81. Infected individuals and their families have provided the Inquiry with detailed accounts of their treatment. Some witnesses have stated that, following diagnosis, there were no difficulties accessing treatment.[129] One patient describes that he felt his treating team were doing their best for him but that they '*were having to 'fight' for funding and juggle or prioritise patients to receive treatment*'.[130]

82. Dr Cachia's recollection is that '*from memory, there were no major difficulties in obtaining funding for interferon and/or ribavirin for our patients with HCV. Scientific publications on the efficiency of new treatments do generally precede licensing and funding arrangements and I do remember having to make individual requests for interferon for named patients in the early days. From memory, such requests had to be approved by the liver specialty consultants, which was not a*

[126] PRSE0007002
[127] §45.1 of WITN4028001
[128] §8 of WITN4749001
[129] For example, §20 of WITN2083001
[130] §21 of WITN2192001

problem as Dr Dillon would have already seen the patient and recommended treatment.'[131]

83. The Penrose Inquiry published a detailed account of an individual called Colin, who began treatment with interferon and ribavirin in 1988 and required a liver transplant.[132] Patients have described to this Inquiry treatment with interferon, pegylated interferon and ribavirin from the early 2000s.[133] Later treatments such a boceprevir and telaprevir are also described.[134]

84. June Ward, haemophilia nurse, has told the Inquiry that patients who were newly diagnosed with HCV or never been treated would meet with herself and the consultant and be given '*a full explanation of the disease, disease process, available treatments, risks, tests and expected care.*' She has stated that the Centre '*operated in an open and honest manner and we strived to inform our patients in all aspects of their care so that they could make informed decisions about disease process, tests and treatment.*'[135] She states that '*consent was always sought when organising simple or more complex tests. Treatment options with risks and benefits were clearly explained no matter what treatment was being planned or offered.*'[136] She has stated that patients were informed if their blood was going to be tested for HIV, HBV and HCV.[137] She stated that when most patients received a diagnosis of HCV in the mid to late 1990s '*there were no formal arrangements to have them routinely seen by a clinical psychologist for formal counselling*' but psychological support was provided in later years.[138]

85. One individual infected with HCV describes attempting to commit suicide after his diagnosis and the breakdown of his relationship but being interrupted by a call from his mother.[139] He states that he has never been offered any counselling or

[131] §65.2 of WITN4028001
[132] §6.139 of PRSE0007002
[133] For example, §14 of WITN2192001
[134] §14 of WITN2192001
[135] §17 of WITN4056001
[136] §20 of WITN4056001
[137] §25 of WITN4056001
[138] §29 of WITN4056001
[139] §15 of WITN2290001

psychological support and asked to see a psychiatrist during his second round of treatment but '*the hospital didn't get back to me.*'[140]

HBV

86. In contrast to HCV, there is far less available documentary evidence about HBV. Medical records show that in January 1985 Dr Wilson gave a paediatric patient a HBV vaccination '*because of the risk that he may acquire hepatitis B from the factor VIII concentrate which he receives when necessary.*'[141]

87. Dr Cachia has told the Inquiry that from his recollection there were no patients with chronic HBV who attended the Centre while he was Director.[142]

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June 2021

[140] §31 of WITN2290001
[141] WITN2192006
[142] §58.2 of WITN4028001