SMALLER HAEMOPHILIA CENTRES PRESENTATION

NORTHERN REGION:

(1) CARLISLE

(2) DARLINGTON

(3) MIDDLESBROUGH (CLEVELAND)

(4) SUNDERLAND

(5) WHITEHAVEN

Directors, Facilities and Staffing

1. During the 1970s-1980s, the Directors of the Haemophilia Centres at:

    a. Carlisle included Dr A Inglis (from approximately 1968 to 1978); Dr Terence Jack Deeble (from approximately 1979 to 1981); and Dr Hugh O'Brien, Consultant Haematologist[1] (from approximately 1982 to at least 1986). Dr Inglis was a member of the British Society for Haematology in 1975/6.[2] Dr Deeble was a member of the British Society for Haematology in 1978/9[3] and 1979/80.[4] Dr Deeble has provided a written statement (undated) to the Inquiry.[5] He was a consultant at the Cumberland Infirmary from 1975 to 1982.[6]

    b. Darlington apparently included Dr Tregillus, Dr D C Lamb, and Dr A E S Mustafa. Dr Tregillus was a Senior Consultant Pathologist at Darlington in 1977 and corresponded with Miss Spooner regarding patients treated at Darlington.[7] Dr Lamb is named as Director of the Darlington Haemophilia Centre in the 1978 Annual Returns[8] and was a member of the British Society

[1] PRSE0001088
[2] BSHA0000138
[3] BSHA0000122
[4] BSHA0000114
[5] WITN5247001
[6] WITN5247001 para 1
[7] HCDO0000040_002
[8] HCDO0001251

for Haematology in 1975/6[9] and 1979/80.[10] Dr Mustafa was a member of the British Society for Haematology in 1978/9[11] and 1979/80.[12]

c. Middlesbrough (also known as Cleveland) included Dr R E Potts (1976); Dr Noel Esme Machell Harker (from approximately 1976 to 1982); Dr Geoffrey P Summerfield (1983); and Dr J E Chandler (from approximately 1984 onwards). Dr Potts relinquished his duties as Director in February 1976 and Dr Harker took over.[13] Dr Harker was a member of the British Society for Haematology in 1975/6[14] and 1979/80.[15] Dr Summerfield was a member of the Advisory Committee on the Virological Safety of Blood.[16] He was invited to serve on the expert advisory committee by letter dated 10 March 1989.[17]

d. Sunderland included Dr A MacKenzie (from approximately 1976 to 1982); and Dr David Kenston Goff (from 1983 onwards).[18] Dr Goff has provided a written statement to the Inquiry dated 27 February 2021,[19] and a second written statement dated 21 April 2021.[20] He was a Consultant Haematologist in Sunderland from 1978 to 2004 and part-time Consultant Haematologist from 2004 to 2009. Dr Lesley Kay was also a Consultant Haematologist at Sunderland Royal Infirmary and a transfusion specialist. [21] She was a member of the Working Party of the Regional Transfusion Directors Committee of the NBTS for Autologous Transfusion.[22] In terms of other personnel and facilities at Sunderland, Dr Goff described:

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[9] BSHA0000138
[10] BSHA0000114
[11] BSHA0000122
[12] BSHA0000114
[13] HCDO0000087_004
[14] BSHA0000138
[15] BSHA0000114
[16] See, for example, PRSE0001865,DHSC0006980_002, DHSC0002497_094, and DHSC0003589_051
[17] DHSC0002429_046
[18] CBLA0001619 Minutes of UKHCDO meeting on 13 September 1982 recorded that "*Dr MacKenzie at Sunderland had retired and the new Director was Dr D K Goff*".
[19] WITN5423001
[20] WITN5423002
[21] See, for example, NHBT0083820, HSOC0007935, NHBT0077720, NHBT0077712, NHBT0017614_016, NHBT0077720, DHSC0004753_034, DHSC0004753_035
[22] NHBT0110350, BPLL0007205, BSHA0000013_038, NHBT0110350

"*It started as a 6 bedded unit with 2 out patient rooms gradually expanding to 14 beds, 3 outpatient rooms and a day care centre for chemotherapy, venesection, plasmapheresis etc. Staff included 1 S.H.O. (Medical Rotation), 1 Registrar or Senior Registrar (Regional Haematology rotation). All this was shared with a Consultant colleague Dr Peter Carey who joined me about 1985*".[23]

e. Whitehaven included Dr Philip John Whitehead (Consultant Pathologist and Director of the Haemophilia Centre from 1968 to 1987);[24] and Dr N C West, Consultant Haematologist.[25] Dr Whitehead has provided a written statement to the Inquiry dated 3 May 2021.[26]

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

2. The Haemophilia Centres were based at:[27]

a. Carlisle: Department of Pathology, Cumberland Infirmary, Carlisle, Cumbria, CA2 7HY. The designated Haemophilia Centre Number was 141.

b. Darlington: Memorial Hospital, Hollyhurst Road, Darlington, Co. Durham, DL3 6HX. The designated Haemophilia Centre Number was 142. The Inquiry understands that Darlington was no longer a Centre after 1984.

c. Middlesbrough: Department of Clinical Pathology, Middlesbrough General Hospital, Ayresome Green Lane, Middlesbrough, Cleveland, TS5 5AZ. The designated Haemophilia Centre Number was 143.

[23] WITN5423001 para 6.1
[24] WITN5308001
[25] Named as Director of the Centre in the Annual Returns for 1985 (HCDO0001966) and 1988 (HCDO0002242)
[26] WITN5308001
[27] DHSC0002339_006 as at July 1978; BPLL0010509 as at 8 August 1984 (by which time Darlington was no longer a Centre); DHSC0002263_005 as at 15 February 1985 and HSOC0017344 as at February 1991. HCDO0000119_138.

d. Sunderland: The Royal Infirmary, Durham Road, Sunderland, Tyne and Wear, SR2 7JR. The designated Haemophilia Centre Number was 144.

e. Whitehaven: West Cumberland Hospital, Hensingham, Whitehaven, Cumbria, CA28 8JG. The designated Haemophilia Centre Number was 145.

3. In 1975/1976, Carlisle, Darlington, Middlesbrough, Sunderland and Whitehaven were all part of Northern Regional Health Authority, which was itself part of the Newcastle Supraregion.[28] It is apparent that there was a close relationship between Newcastle Haemophilia Reference Centre and the other Northern Centres. Dr Peter Jones, Consultant Paediatrician at the Royal Victoria Infirmary (RVI), Newcastle, considered that a *"major part of my responsibility was a regional commitment to the care of children and adults with haemophilia…"*.[29] Dr Goff stated that "*any cases of hereditary bleeding disorder diagnosed in Sunderland were to be transferred to Newcastle for treatment*".[30]

4. In the mid to late 1960s, the Newcastle Regional Hospital Board considered a Ministry of Health paper recommending a limit on the number of specialist haemophilia Centres.[31] The Board considered that there might reasonably be three Centres in the region: Newcastle, Carlisle and Middlesbrough (the first two having already been designated at that time).[32]

5. At a meeting of the Medical Advisory Committee at North Riding Infirmary on 8 February 1971, it was reported that "*Teesside patients suffering from haemophilia had been taken as emergencies to hospitals in Newcastle for treatment. Dr Elsworth, on behalf of Dr Donaldson, expressed concern lest haemophiliacs' condition should deteriorate whilst being transported from Teesside to Newcastle*".[33] It was recorded

[28] OXUH0000863_002, CBLA0000699
[29] WITN0841007 at p.1
[30] WITN5423002 para 1.1
[31] TYWE0000036_001
[32] TYWE0000036_001 p. 3
[33] TEAR0000001 p. 6

that a request be made "*to arrange for Teesside to be nominated as an official centre for the treatment of haemophilia…*" and that Dr Stewart had reported that "*there were arrangements for a diagnostic and registration centre to be located at Newcastle and for sub-centres at Carlisle and Teesside*".[34] Furthermore, "*Dr Williams reminded the meeting that haemophiliacs had open access to the medical and paediatric wards at Middlesbrough General Hospital where they could report for treatment as and when they considered it necessary*".[35] The meeting resolved "*to recommend that in the patients' interests haemophiliac patients requiring urgent treatment should in the first instance attend at the Middlesbrough General Hospital (medical wards for adults, paediatric department for children) so that their condition could be assessed, any immediate treatment instituted and the need for transfer to Newcastle determined…*"[36]

6. In March 1974, the Newcastle Regional Hospital Board proposed the development of a Regional Haemophilia Centre at the Royal Victoria Infirmary, Newcastle, together with further centres at the Royal Infirmary, Sunderland; Middlesbrough General Hospital; Darlington Memorial Hospital; Cumberland Infirmary, Carlisle; and West Cumberland Hospital.[37] This proposal had been prompted by Dr Jones.[38] It was "*suggested that all patients with bleeding disorders requiring any form of hospital treatment should be referred in the first instance to the appropriate consultant for the area, or his deputy*".[39] However, that the "*Newcastle Centre will continue to be responsible for all major surgery and the treatment of complications*".[40]

7. A report to the Newcastle Area Health Authority by Dr Jones in November 1975 described the arrangement as follows:[41]

> "*<u>The position in the Northern Region</u>*

[34] TEAR0000001 p. 6
[35] TEAR0000001 p. 6
[36] TEAR0000001 p. 6
[37] TYWE0000036_002
[38] TYWE0000036_003, TYWE0000036_004
[39] TYWE0000036_004
[40] TYWE0000036_004
[41] PJON0000099_001

With the reorganisation of the UK Haemophilia Centre network (new DHSS memorandum for circulation in the near future) the RVI becomes a Reference Centre for the Northern Region, with associate centres at Sunderland, Middlesbrough, Darlington, Carlisle and Whitehaven. Newcastle therefore has a prime responsibility for the management of all patients with hereditary bleeding disorders in the Region. In practice haemophiliacs receive immediate care at their local centres, or, in a few cases, at District General Hospitals, known to the Centre network. The Newcastle Centre Director is contracted to the RHA with consultant responsibility throughout the Region, rather than to one hospital or one group of hospitals."

8. At a meeting on 14 April 1976, the North Tees Community Health Council considered a report prepared on the facilities available for haemophiliacs within the area.[42] The Council "*considered the matter and felt that Cleveland should have a centre of at least 'Associate' level*".[43] Furthermore, it was "*felt that local facilities up to 'Haemophilia Centre' level would be of great benefit to the community and the Council would welcome such provision if it could be made at minimal cost*".[44]

9. In the 1977 spring newsletter of the Northumbrian Branch of the Haemophilia Society, Dr Jones wrote:[45]

> "*… A group of interested doctors and dentists in some of the Region major hospitals had agreed to work closely together in the management of haemophiliacs, and the Northern Regional Haemophilia Service was formed. New Centres were established in Sunderland Middlesbrough, Darlington and Whitehaven and were officially recognised by the Department of Health and Social Security. Together with Carlisle and Newcastle this network now provides haemophilia cover for patients throughout the Region*."

[42] TEAR0000022
[43] TEAR0000022 p. 2
[44] TEAR0000022 p. 2
[45] HSOC0021635 p. 5. For the position in 1991, see UHMB0000005_019

10. In 1980, the associated Centres in Carlisle, Cleveland (Middlesbrough), Sunderland, Whitehaven and Newcastle together served a population of 3.3million.[46]

11. In a "*Report to RHA and DHA*" dated October 1985, Dr Jones described the regional arrangements as follows:[47]

> "*The Newcastle Centre provides a regional service to haemophiliacs and their families. The staff work closely with colleagues in other Centres at Sunderland, Middlesbrough, Carlisle and Whitehaven. With their help and approval Newcastle maintains responsibility for surgery and the management of complications, the home therapy and prophylaxis programmes, and the regular follow-up of all patients. In effect this means that supplies of all therapeutic material are all channelled through the Newcastle Centre.*"

12. It is understood that Carlisle, Darlington, Middlesbrough, Sunderland and Whitehaven as part of the Northern Region were supplied by the Regional Transfusion Centre in Newcastle.[48] In a letter dated 11 July 1979 to Mr Barker, Northern Regional Health Authority, Mr Dickinson of the Cleveland Area Health Authority stated that "*The South Tees Department of Clinical Pathology obtains a great part of its blood products from the Regional Transfusion Centre in Newcastle*".[49]

13. In a letter dated 4 October 1984, N Pettet of BPL wrote to Dr Summerfield at Middlesbrough (copying in Dr Collins, Director of the Regional Transfusion Centre in Newcastle) stating that "*Until the new factory is commissioned for full manufacture in 1986 we shall be unable to fulfil the national demand for blood products ie factor VIII and Albumin*".[50] Mr Pettet stated that further increased supplies would be provided to the Northern Region via the Regional Transfusion Centre and advised Dr Summerfield to contact the Regional Transfusion Centre to obtain supplies of blood products.[51]

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[46] HSOC0021607 p. 9
[47] PJON0000101_001
[48] TYWE0000410. WITN5308001 p. 3
[49] DHSC0002193_074
[50] TYWE0000051_007
[51] TYWE0000051_007

14. By letter dated 11 June 1985, Dr Summerfield wrote to Dr Collins at the Regional Transfusion in Newcastle setting out the "*major users of blood products in the South Tees District*".[52]

15. By letter dated 7 July 1986, Dr Goff (Sunderland) wrote to Dr Donaldson, Regional Medical Officer at the Northern Regional Health Authority, on behalf of the Northern Region Consultant Haematologists Group expressing "*extreme concern…* at *the precarious state of the Regional Blood Transfusion Service*".[53] In particular, the RBTS was said to be "*underfunded and understaffed for the work that modern medicine requires of it and, in this respect, compares most unfavourably with any other RBTS of equivalent size*".[54] Concerns were expressed about the shortfall of plasma and that the "*existing solution is to purchase very expensive commercial products*".[55]

Number of Patients Registered and/or Treated at the Centres

16. A list of Haemophilia Centres in around 1975 suggests that there were: [56]

    a. 8 patients with haemophilia A at Carlisle;
    b. 114 patients at Newcastle including patients treated at Associate Centres in Darlington, Middlesbrough, Sunderland and Whitehaven.

17. In a table enclosed under cover of letter dated 19 December 1977 from Dr Rizza to Dr Maycock, there were in 1976:[57]

    a. 16 patients with haemophilia A, 0 carriers of haemophilia A and 3 patients with von Willebrand's disease at Carlisle;

[52] BPLL0000839_004. See also BPLL0000839_009
[53] NHBT0103432_005
[54] NHBT0103432_005
[55] NHBT0103432_005
[56] OXUH0000863_002
[57] CBLA0000699 p. 6

b. 0 patients with haemophilia A, 0 carriers of haemophilia A and 0 patients with von Willebrand's disease at Darlington;
c. 30 patients with haemophilia A, 0 carriers of haemophilia A and 0 patients with von Willebrand's disease at Middlesbrough;
d. 0 patients with haemophilia A, 0 carriers of haemophilia A and 0 patients with von Willebrand's disease at Sunderland;
e. 5 patients with haemophilia A, 0 carriers of haemophilia A and 0 patients with von Willebrand's disease at Whitehaven.

18. The number of patients registered and/or treated at each Centre according to the Annual Returns and other evidence received by the Inquiry is set out below.

Carlisle

19. A survey completed by Dr Inglis indicated that there were 5 patients regularly treated at Carlisle at roughly the end of 1972.[58]

20. In the following years, the numbers of patients registered and/or treated at Carlisle from the available evidence in the Annual Returns were as follows:

a. 1976: The Annual Returns for 1976, signed by Dr Inglis, show that Carlisle treated 16 patients with haemophilia A, 0 patients with Christmas disease, and 1 patient with von Willebrand's disease.[59] No patients were on regular home therapy.[60]

b. 1977: The Annual Returns for 1977, signed by Dr Inglis, show that Carlisle treated 12 patients with haemophilia A, 0 patients with Christmas disease, and

[58] BPLL0008111 p. 9
[59] HCDO0001066
[60] HCDO0001066 p. 1

1 patient with von Willebrand's disease.[61] It appears that no patients were on regular home therapy.[62]

c. 1978: The Annual Returns for 1978, signed by Dr Deeble, show that Carlisle treated 14 patients with haemophilia A, 1 patient with Christmas disease, and 3 patients with von Willebrand's disease.[63] It appears that no patients were on regular home therapy.[64]

d. 1979: The Annual Returns for 1979, signed by Dr Deeble, show that Carlisle treated 8 patients with haemophilia A (1 visitor), 0 patients with Christmas disease, and 3 patients with von Willebrand's disease.[65] It appears that no patients were on regular home therapy.[66]

e. 1980: The Annual Returns for 1980, signed by Dr Deeble, show that Carlisle treated 4 patients with haemophilia A and 1 patient with von Willebrand's disease.[67]

f. 1981: The Annual Returns for 1981, signed by Dr Deeble, do not specify the number of patients treated at Carlisle during that year.[68]

g. 1982: The Annual Returns for 1982, signed by Dr O'Brien, show that Carlisle treated 1 patient with haemophilia A, 1 patient with von Willebrand's disease and 1 patient with haemophilia B.[69]

[61] HCDO0001147
[62] HCDO0001147 p. 2
[63] HCDO0001242
[64] HCDO0001242
[65] HCDO0001311
[66] HCDO0001311 p. 2
[67] HCDO0001406
[68] HCDO0001504
[69] HCDO0001607

h. 1983: The Annual Returns for 1983, signed by Dr O'Brien, show that Carlisle treated 8 patients with haemophilia A, 1 carrier of haemophilia A, and 0 patients with von Willebrand's disease.[70]

i. 1984: The Inquiry does not have the complete Annual Returns for Carlisle in 1984.

j. 1985: The Annual Returns for 1985, signed by Dr O'Brien, show that Carlisle treated 3 patients with haemophilia A and 1 patient with von Willebrand's disease.[71]

k. 1986: The Annual Returns for 1986, signed by Dr O'Brien, show that Carlisle treated 5 patients with haemophilia A and 2 patients with von Willebrand's disease.[72]

Darlington

21. The Inquiry has limited Annual Returns for Darlington:

a. 1976: As acknowledged in a letter from Miss Spooner dated 29 September 1977, Dr Tregillus reported that no patients were treated at Darlington in 1976.[73]

b. 1978: The Annual Returns for 1978, signed by D C Lamb, show that Darlington treated 1 patient with haemophilia A.[74]

Middlesbrough

[70] HCDO0001703 p. 1
[71] HCDO0001891
[72] HCDO0001987
[73] HCDO0000040_002, HCDO0000040_001
[74] HCDO0001251

22. In the following years, the numbers of patients registered and/or treated at Middlesbrough from the available evidence in the Annual Returns were as follows:

a. 1976: The Annual Returns for 1976, signed by Dr Harker, show that Middlesbrough treated 30 patients with haemophilia A.[75] A covering letter dated 4 October 1977 from Penny Taylor, Registrar, to Miss Spooner stated that "*A lot of the patients treated at Cleveland are on home therapy from Newcastle*".[76]

b. 1977: The Annual Returns for 1977, signed by Dr Harker, show that Middlesbrough treated 21 patients with haemophilia A and 5 patients with von Willebrand's disease.[77]

c. 1978: The Annual Returns for 1978, signed by Dr Harker, show that Middlesbrough treated 17 patients with haemophilia A, 3 patients with Christmas disease and 2 patients with von Willebrand's disease.[78]

d. 1979: The Annual Returns for 1979, signed by Dr Harker, show that Middlesbrough treated 15 patients with haemophilia A, 4 patients with Christmas disease and 2 patients with von Willebrand's disease.[79]

e. 1980: The Annual Returns for 1980, signed by Dr Harker, show that Middlesbrough treated 14 patients with haemophilia A, 3 patients with von Willebrand's disease, and 3 patients with haemophilia B.[80]

[75] HCDO0001101
[76] HCDO000087_002
[77] HCDO0001186
[78] HCDO0001283
[79] HCDO0001352
[80] HCDO0001449

f. 1981: The Annual Returns for 1981, signed by Dr Harker, show that Middlesbrough treated 12 patients with haemophilia A, 3 patients with von Willebrand's disease, and 4 patients with haemophilia B.[81]

g. 1982: The Annual Returns for 1982, signed by Dr Harker, show that Middlesbrough treated 13 patients with haemophilia A, 3 patients with von Willebrand's disease, and 4 patients with haemophilia B.[82]

h. 1983: The Annual Returns for 1983, signed by Dr Summerfield, show that Middlesbrough treated 7 patients with haemophilia A, 3 patients with von Willebrand's disease, and 3 patients with haemophilia B.[83]

i. 1984: The Annual Returns for 1984, signed by Dr Chandler, show that t Middlesbrough treated 6 patients with haemophilia A, 2 patients with von Willebrand's disease, and 1 patient with haemophilia B.[84]

j. 1985: The Annual Returns for 1985, signed by Dr Chandler, show that Middlesbrough treated 9 patients with haemophilia A, 4 patients with von Willebrand's disease, and 1 patient with haemophilia B.[85]

k. 1986: The Annual Returns for 1986, signed by Dr Chandler, show that Middlesbrough treated 7 patients with haemophilia A,2 patients with von Willebrand's disease,[86] and 3 patients with haemophilia B.[87]

23. A List of Centres with Patients under 19 years of age includes Middlesbrough which suggests that children were treated at the Centre.[88] A Directory of Haemophilia

[81] HCDO0001550
[82] HCDO0001649
[83] HCDO0001746
[84] HCDO0001840
[85] HCDO0001933
[86] HCDO0002030
[87] HCDO0002030. The Annual Returns for 1987 are at HCDO0002116, 1998 are at HCDO0002209, and 1989 are at HCDO0002302 (all signed by Dr Chandler).
[88] HCDO0000013_269

Centres produced by the Haemophilia Society and BPL also indicates that children were treated at Middlesbrough.[89]

Sunderland

24. According to Dr Goff, all patients diagnosed in the Sunderland area were transferred to Newcastle for treatment.[90] He stated that neither he nor his department was asked to take over the care of any haemophiliac patients residing in the Sunderland Hospitals catchment area.[91]

25. The Inquiry has received evidence from an anonymous witness whose husband, a severe haemophiliac, was initially under the care of the Royal Infirmary Sunderland "*but this was later changed to Royal Victoria Infirmary in Newcastle ("RVI"), where he attended for most, if not all, of his medical appointments*".[92]

26. The Inquiry does not have a complete set of Annual Returns for Sunderland. From the limited information available:

    a. 1976: It was noted that "*Sunderland Royal Infirmary phoned to say that you have got (or should have) all the returns he has for 1976*" and "*Return sent only to Newcastle*".[93]

    b. 1979: The Annual Returns for 1979 show that 1 patient with haemophilia A was treated at Sunderland.[94]

    c. 1980: The Annual Returns for 1980, signed by Dr MacKenzie, show that Sunderland treated 1 patient with von Willebrand's disease and 1 patient with haemophilia B.[95]

[89] HSOC0017344
[90] WITN5423002 para 1.1
[91] WITN5423002 para 2.1.1
[92] WITN2133001 para 11
[93] HCDO0000031_002
[94] HCDO0001376
[95] HCDO0001473

d. 1983: In a letter dated 15 June 1984, Dr Goff wrote to Miss Spooner at the Oxford Haemophilia Centre stating "*I can give you a nil return for last year. We had at least a couple of patients admitted but we immediately transferred them to Newcastle*".[96]

e. 1986: By letter dated 24 March 1987, Miss Spooner wrote to Dr Goff acknowledging "*Nil Returns for 1986*".[97]

Whitehaven

27. In a letter dated 18 June 1987 to Dr Rizza at Oxford Haemophilia Centre, Dr West described the provision at Whitehaven:[98]

> "*…Whitehaven is a very small Haemophilia Centre and the majority of the patients in the area are on home treatments and have regular review at the Regional Centre in Newcastle, hence, my function seems to be purely as an emergency station for locals who need treatment urgently and cannot get to Newcastle or for holidaymakers…*"

28. In a letter dated 10 April 1995 to Mr Barker of the Haemophilia Society, Dr West described:[99]

> "*Here at Whitehaven I am afraid the Haemophilia Centre has rather fallen into decline due to the fact that most of the haemophiliacs I treated when I first came here have died of Aids. This was a tragic and demoralising experience.*
>
> *I now act as an associate centre with the main expertise coming from the Regional centre in Newcastle. However, I feel that it is important for us to be*

[96] HCDO0000190_003
[97] HCDO0000295_002
[98] HCDO0000293_002
[99] BART0000648_010

included in any directory because I occasionally treat patients who have had a bleed while on holiday in the Lake District, and given the distance to any alternative treatment centre, it think this provides a useful facility."

29. The Inquiry does not have a complete set of Annual Returns for Whitehaven. It appears from the limited information available that the following numbers of patients were registered and/or treated at Whitehaven:

    a. 1976: The Annual Returns for 1976, signed by Dr Whitehead, show that Whitehaven treated 5 patients with haemophilia A and 0 patients with Christmas disease.[100] It appears that 3 patients were on home treatment which was administered from RVI Newcastle.[101]

    b. 1977: The Annual Returns for 1977, signed by Dr Whitehead, show that Whitehaven treated 4 patients with haemophilia A and 0 patients with Christmas disease.[102]

    c. 1979: The Annual Returns for 1979, with no named Director, show that Whitehaven treated 3 patients with haemophilia A and 0 patients with Christmas disease.[103]

    d. 1981: A handwritten note suggests that Dr Bird at Whitehaven did not receive the forms.[104] It appears from the note that 2 patients were treated at Whitehaven in 1981.[105]

[100] HCDO0000102_002
[101] HCDO0000102_002 p. 1
[102] HCDO0001218 p. 2
[103] HCDO0001383 p. 1
[104] HCDO0001585
[105] HCDO0001585

e. 1985: The Annual Returns for 1985, signed by Dr West, show that Whitehaven treated 1 patient with haemophilia A and 1 patient with von Willebrand's disease.[106]

f. 1986: A letter dated 18 June 1987 from Dr West to Dr Rizza at the Oxford Haemophilia Centre stated that only one patient was treated in 1986 who was transferred to Newcastle for further management.[107]

g. 1988: The Annual Returns for 1988, signed by Dr West, show that Whitehaven treated 1 patient with haemophilia A, 1 patient with haemophilia B and 0 patient with von Willebrand's disease.[108]

30. Data from the Northern Centres was contributed to published studies such as: "*Jaundice and Antibodies Directed Against Factors VIII and IX in Patients Treated for Haemophilia or Christmas Disease in the United Kingdom*" by Rosemary Biggs, [109] "*Haemophilia Treatment in the United Kingdom from 1969 to 1974*" by Rosemary Biggs,[110] and "*Treatment of haemophilia and related disorders in Britain and Northern Ireland during 1976-80*" by C R Rizza and Rosemary J D Spooner[111] by:

a. Dr Inglis and Dr Deeble of Cumberland Infirmary, Carlisle;[112]
b. Dr Mustafa of Memorial Hospital, Darlington;[113]
c. Dr Potts and Dr Harker of Middlesbrough General Hospital, Middlesbrough;[114]
d. Dr MacKenzie of the Royal Infirmary, Sunderland;[115] and
e. Dr Whitehead of West Cumberland Hospital, Whitehaven.[116]

[106] HCDO0001966
[107] HCDO0000293_002
[108] HCDO0002242
[109] HCDO0000581
[110] PRSE0004645
[111] HCDO0000586
[112] PRSE0004645, HCDO0000581 and HCDO0000586
[113] PRSE0004645
[114] PRSE0004645 and HCDO0000586
[115] PRSE0004645
[116] PRSE0004645 and HCDO0000586

Treatment policies and blood product usage

31. In a "*Report to RHA and DHA*" dated October 1985, Dr Jones stated that, due to regional arrangements, "*supplies of therapeutic material are all channelled through the Newcastle Centre*".[117] The Report sets out the total use of factor VIII blood product in Newcastle and other Centres for the previous 3 years in Table 2.[118]

32. In a letter dated 23 February 1988 to the Regional Medical Officer at the Northern Regional Health Authority, Dr Jones enclosed statistics showing how use of blood products in the Northern Region had changed over time.[119] Figures from 1975 onwards included the associated treatment Centres in Sunderland, Middlesbrough and Whitehaven.[120] Dr Jones noted that *"The supply of NHS concentrate to the Northern Region has been, to say the least, erratic and the inevitable gross shortfall has been made up with commercial concentrate."*[121] He stated that *"... we started to use heat treated concentrates in the Northern Region in December 1984*".[122]

33. A report on the "*Collection of Fresh Frozen Plasma in the Northern Region*" recommended an increase in the level of plasma collection in the Northern Region.[123] The background to the plasma procurement programme in the Northern Region was summarised as follows:[124]

> "*6... In the late 1970s, the demand in the Region for FVIII increased rapidly, exceeding the available supply from the Regional Transfusion Service. At that time, a decision was made to purchase commercial VIII, rather than invest in plasma procurement through the RTC... By 1986/87, FVIII demand and costs had risen to such an extent that over £1 million was being spent annually on FVIII alone.*"

[117] PJON0000101_001
[118] PJON0000101_001 p. 10
[119] BPLL0002848_001
[120] BPLL0002848_001 p. 1
[121] BPLL0002848_001 p. 2
[122] BPLL0002848_001 p.2
[123] NHBT0001580 p. 2
[124] NHBT0001580 p. 3-4

34. It was noted that the Northern Region was the largest per capita purchaser of factor VIII.[125] It was considered "*too risky and too costly to continue to rely on commercially purchased products*" and it was recommended that "*the Northern Region should secure an alternative means of procurement as soon as possible*".[126]

35. In the minutes of the UKHCDO meeting of 21 September 1990, it is recorded that Dr Jones stated that *"The Northern Region was opting for commercial concentrates due to their lower price and they were fully licensed…"*[127]

36. The blood products used by each Centre according to the Annual Returns and other evidence received by the Inquiry is set out below.

Carlisle

37. According to a survey response by Dr Inglis at approximately the end of 1972, the preferred treatment for patients at Carlisle was some cryoprecipitate and some freeze-dried concentrate.[128] The Centre required 430 single donations of cryoprecipitate and 2 bottles of concentrate for its present treatment policy. If the supply of cryoprecipitate and/or concentrate were not restricted by shortage, Dr Inglis estimated that Carlisle would require 500 donations of cryoprecipitate and 10 bottles of freeze-dried concentrate annually.[129]

38. Dr Inglis attended a Joint Meeting of Directors of Haemophilia Centres and Blood Transfusion Directors held at the Regional Blood Transfusion Centre in Sheffield on 31 January 1974 where the future of factor VIII requirements in the UK was discussed.[130]

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[125] NHBT0001580 p. 5, para 19
[126] NHBT0001580 p. 7, para 24
[127] BART0002382. For the position in 1991, see UHMB0000005_019
[128] BPLL0008111 p. 9
[129] BPLL0008111 p. 9
[130] CBLA0000187

39. Dr Deeble stated that "*To my knowledge, no FVIII concentrate was prescribed by the Haematology Dept during my tenure there; it would have been inappropriate*".[131]

40. According to data contained in the Annual Returns, Carlisle used the following blood products:

    a. 1976: To treat 16 patients with haemophilia A, Carlisle used 686 packs of cryoprecipitate.[132] No factor VIII concentrates appear to have been used to treat haemophilia A patients in 1976.[133] To treat 1 patient with von Willebrand's disease, Carlisle used 6 packs of cryoprecipitate.[134] Again, no factor VIII concentrates appear to have been used to treat von Willebrand's disease patients in 1976.[135]

    b. 1977: To treat 12 patients with haemophilia A, Carlisle used 825 packs of cryoprecipitate.[136] No factor VIII concentrates appear to have been used to treat haemophilia A patients in 1976.[137] To treat 1 patient with von Willebrand's disease, Carlisle used 50 packs of cryoprecipitate.[138] Again, no factor VIII concentrates appear to have been used to treat von Willebrand's disease patients in 1977.[139]

    c. 1978: To treat 14 patients with haemophilia A, Carlisle used 42,000 units of cryoprecipitate and 3 bottles / 870 units of NHS factor VIII.[140] No commercial factor VIII concentrates appear to have been used to treat haemophilia A patients in 1976.[141] To treat 1 patient with Christmas disease, the Centre used

[131] WITN5247001 para 2
[132] HCDO0001066 p. 1
[133] HCDO0001066 p. 1
[134] HCDO0001066 p. 2
[135] HCDO0001066 p. 2
[136] HCDO0001147 p. 1
[137] HCDO0001147 p. 1
[138] HCDO0001147 p. 4
[139] HCDO0001147 p. 4
[140] HCDO0001242 p. 4
[141] HCDO0001242 p. 4

560 units of factor IX concentrate.[142] To treat 3 patients with von Willebrand's disease, Carlisle used 369 bags of cryoprecipitate and 2 bottles of FFP.[143] Again, no factor VIII concentrates appear to have been used to treat von Willebrand's disease patients in 1978.[144]

d. 1979: To treat 8 patients with haemophilia A, Carlisle used: [145]

   i. 2 bottles / 600 units of plasma;
   ii. 680 bottles / 47,600 units of cryoprecipitate;
   iii. 15,525 units of NHS factor VIII;
   iv. 5,502 units of Armour Factor VIII (Factorate); and
   v. 23,700 units of Hyland Factor VIII (Kryobulin).

e. To treat 3 patients with von Willebrand's disease, Carlisle used 92 bags / 6,500 units of cryoprecipitate.[146]

f. 1980: To treat 4 patients with haemophilia A, Carlisle used 25,690 units (estimated) of cryoprecipitate in hospital. [147] No cryoprecipitate was used for home treatment.[148] It appears that no factor concentrates were used in hospital or at home.[149] To treat 1 patient with von Willebrand's disease, Carlisle used 700 units (estimated) of cryoprecipitate.[150]

g. 1981: To treat patients with haemophilia A, Carlisle used 420 units of cryoprecipitate, 8,724 units of NHS factor VII, and 2,096 Armour Factor VIII (Factorate) in hospital. [151] It was noted that the amounts used for home

[142] HCDO0001242 p. 4
[143] HCDO0001242 p. 8
[144] HCDO0001242 p. 8
[145] HCDO0001311 p. 1
[146] HCDO0001311 p. 5
[147] HCDO0001406 p. 1
[148] HCDO0001406 p. 1
[149] HCDO0001406 p. 1
[150] HCDO0001406 p. 1
[151] HCDO0001504 p. 1

treatment were "*monitored from Newcastle*".[152] To treat patients with von Willebrand's disease, Carlisle used 6,300 units of cryoprecipitate.[153]

h. 1982: To treat 1 patient with haemophilia A, it appears that Carlisle used 18 bags of cryoprecipitate, and 265 units of NHS factor VIII in hospital. [154] To treat 1 patient with von Willebrand's disease, Carlisle used 68 bags of cryoprecipitate.[155] To treat 1 patient with haemophilia B, the Centre used 1,450 units of NHS factor IX.[156] It appears that no commercial concentrates were used by Carlisle in 1982.[157]

i. 1983: To treat 8 patients with haemophilia A, Carlisle used 13,370 units of cryoprecipitate in hospital, 14,270 units of NHS factor VIII in hospital and 4,600 units of NHS factor VIII for home treatment. [158] To treat 1 carrier of haemophilia A, Carlisle used 280 units of cryoprecipitate.[159] It appears that no commercial concentrates were used by the Centre in 1983.[160]

j. 1984: The Inquiry does not have the complete Annual Returns for Carlisle in 1984.

k. 1985: To treat 3 patients with haemophilia A, Carlisle used 7,350 units of cryoprecipitate in hospital. To treat 1 patient with von Willebrand's disease, Carlisle used 420 units of cryoprecipitate.[161] It appears that no factor VIII concentrates were used by Carlisle in 1985 in hospital or for home treatment. [162]

[152] HCDO0001504 p. 1
[153] HCDO0001504 p. 1
[154] HCDO0001607 p. 1
[155] HCDO0001607 p. 1
[156] HCDO0001607 p. 2
[157] HCDO0001607
[158] HCDO0001703 p. 1
[159] HCDO0001703 p. 1
[160] HCDO0001703
[161] HCDO0001891
[162] HCDO0001891

l. 1986: To treat 5 patients with haemophilia A, Carlisle used 25,060 units of cryoprecipitate and 10,164 units of Alpha Factor VIII (Profilate) in hospital.[163] To treat 2 patients with von Willebrand's disease, Carlisle used 1,920 units of cryoprecipitate in hospital.[164]

41. An Inquiry witness was treated with factor VIII blood products for nose operations at Carlisle in 1983 and at Newcastle in 1988.[165] He believes that, as a result of being given factor VIII blood products during both operations, he contracted hepatitis C.[166] The witness stated that he was "*not given any information prior to either of the operations*".[167]

42. There is evidence that Dr O'Brien met with a Cutter representative on 31 July 1986 to discuss the use of Koate HT. [168] He was provided with a copy of the Allain paper which "*which showed that none of the patients showed signs of seroconversion and a reduced risk of transmission of non A non B hepatitis*".[169] Dr West also appears to have been present at the meeting where he "*raised the question of the "AIDS" virus not being fully inactivated by the heat treating process*".[170]

Darlington

43. The Inquiry has limited Annual Returns for Darlington:

a. 1978: To treat 1 patient with haemophilia A, Darlington used 5 bottles of NHS factor VIII.[171]

[163] HCDO0001987 p. 1
[164] HCDO0001987
[165] WITN2283001 para 4. The witness' wife has provided a statement at WITN2987001 .
[166] WITN2283001 para 4
[167] WITN2283001 para 5
[168] BAYP0000008_347
[169] BAYP0000008_347
[170] BAYP0000008_348
[171] HCDO0001251

44. In July 1986, it appears that Armour wrote to all UK Haemophilia Centre Directors, including Dr Mustafa at Darlington, recommending the return of all non-donor tested Factorate.[172] It is not clear whether Factorate or other commercial concentrates were in fact used at Darlington.

Middlesbrough

45. According to data contained in the Annual Returns, Middlesbrough used the following blood products from 1976 onwards:

    a. 1976: To treat 30 patients with haemophilia A, Middlesbrough used 1,605 bottles of cryoprecipitate and 203 bottles of Hemofil.[173]

    b. 1977: To treat 21 patients with haemophilia A, Middlesbrough used 1,416 bottles / 99,120 units of cryoprecipitate and 325 bottles / 78,000 units of Hemofil.[174] To treat 5 patients with von Willebrand's disease, Middlesbrough used 1 bottle of plasma and 64 bottles of cryoprecipitate.[175] In relation to home treatment, it was noted that "*The Home Treatment programme is run from the Newcastle-upon-Tyne Reference Centre and patients are given their supplies by Newcastle*".[176]

    c. 1978: To treat 17 patients with haemophilia A, Middlesbrough used 997 bottles / 69,790 units of cryoprecipitate, 69 bottles / 17,250 units of NHS factor VIII, and 181 bottles / 743,440 units of Hemofil.[177] To treat 3 patients with Christmas disease, Middlesbrough used 36 bottles / 20,160 units of NHS factor IX.[178] To treat 2 patients with von Willebrand's disease, Middlesbrough used 29 bottles of cryoprecipitate.[179]

[172] ARMO0000554
[173] HCDO0001101
[174] HCDO0001186 p. 4
[175] HCDO0001186 p. 3
[176] HCDO0001186 p. 5
[177] HCDO0001283 p. 1
[178] HCDO0001283 p. 1
[179] HCDO0001283 p. 6

d. 1979: To treat 15 patients with haemophilia A, Middlesbrough used 1,071 bottles / 74,970 units of cryoprecipitate, and 77 bottles / 19,635 units of NHS factor VIII.[180] To treat 3 patients with Christmas disease, Middlesbrough used 60 bottles / 38,625 units of NHS factor IX.[181] To treat 2 patients with von Willebrand's disease, Middlesbrough used 46 bottles / 3,220 units of cryoprecipitate.[182] It appears that no commercial concentrates were used by Middlesbrough in 1979.

e. 1980: To treat 14 patients with haemophilia A, Middlesbrough used 1 bag of FFP, 26,520 units of cryoprecipitate, 6,625 units of NHS factor VIII, and 2,450 units of Armour Factor VIII (Factorate) in hospital.[183] To treat 3 patients with von Willebrand's disease, Middlesbrough used 12,950 units of cryoprecipitate in hospital.[184] To treat 3 patients with haemophilia B, Middlesbrough used 39,775 units of NHS factor IX.[185]

f. 1981: To treat 12 patients with haemophilia A, Middlesbrough used 27,860 units of cryoprecipitate and 5,800 units of NHS factor VIII in hospital, and 2,650 units of NHS factor VIII for home treatment.[186] To treat 3 patients with von Willebrand's disease, Middlesbrough used 12,460 units of cryoprecipitate in hospital.[187] To treat 4 patients with haemophilia B, Middlesbrough used 7,940 units of NHS factor IX.[188] It appears that no commercial concentrates were used at Middlesbrough in 1981.

[180] HCDO0001352 p. 1
[181] HCDO0001352 p. 1
[182] HCDO0001352 p. 6
[183] HCDO0001449 p. 1
[184] HCDO0001449 p. 1
[185] HCDO0001449 p. 3
[186] HCDO0001550 p. 1
[187] HCDO0001550 p. 1
[188] HCDO0001550 p. 2

g. 1982: To treat 13 patients with haemophilia A, Middlesbrough used 31,360 units of cryoprecipitate and 1,735 units of NHS factor VIII in hospital.[189] To treat 3 patients with von Willebrand's disease, Middlesbrough used 2,000 units of cryoprecipitate in hospital.[190] To treat 4 patients with haemophilia B, Middlesbrough used 12,735 units of NHS factor IX in hospital.[191] It appears that no commercial concentrates were used in 1982.

h. 1983: To treat 7 patients with haemophilia A, Middlesbrough used 29,330 units of cryoprecipitate, 7,470 units of NHS factor VIII, and 2,000 units of Cutters Factor VIII (Koate) in hospital.[192] To treat 3 patients with von Willebrand's disease, Middlesbrough used 6,090 units of cryoprecipitate in hospital.[193] To treat 3 patients with haemophilia B, Middlesbrough used 5,760 units of NHS factor IX in hospital.[194]

i. 1984: To treat 6 patients with haemophilia A, Middlesbrough used 54,980 units of cryoprecipitate, and 1,920 units of NHS factor VIII in hospital.[195] To treat 2 patients with von Willebrand's disease, Middlesbrough used 5,250 units of cryoprecipitate in hospital.[196] To treat 1 patient with haemophilia B, Middlesbrough used 9,825 units of NHS factor IX in hospital.[197] It appears that no commercial concentrates were used at Middlesbrough in 1984.

j. 1985: To treat 9 patients with haemophilia A, Middlesbrough used 48,720 units (696 bags) of cryoprecipitate, and 400/ugm DDAVP in hospital.[198] To treat 4 patients with von Willebrand's disease, Middlesbrough used 4,830 units (69 bags) of cryoprecipitate in hospital.[199] To treat 1 patient with haemophilia

[189] HCDO0001649 p. 1
[190] HCDO0001649 p. 1
[191] HCDO0001649 p. 2
[192] HCDO0001746 p. 1
[193] HCDO0001746 p. 1
[194] HCDO0001746 p. 2
[195] HCDO0001840 p. 1
[196] HCDO0001840 p. 2
[197] HCDO0001840 p. 2
[198] HCDO0001933 p. 1
[199] HCDO0001933 p. 1

B, Middlesbrough used 2,614 units of NHS factor IX in hospital.[200] It appears that no commercial concentrates were used at Middlesbrough in 1985.

k. 1986: To treat 7 patients with haemophilia A, Middlesbrough used 809 packs of cryoprecipitate, 13,795 units of Alpha Factor VIII (Profilate) and 250/ugm DDAVP Tranexamic Acid in hospital.[201] To treat 2 patients with von Willebrand's disease, Middlesbrough used 6 packs of cryoprecipitate in hospital.[202] To treat 3 patients with haemophilia B, Middlesbrough used 2,200 units of NHS factor IX and 1,180 units of Profilate HT in hospital.[203]

46. An Inquiry witness was diagnosed with severe haemophilia A at Middlesbrough when he was 5-6 months old.[204] He was initially treated at Middlesbrough in the early 1960s with "*large amounts of blood plasma by transfusion*".[205] He stated that "*[t]his had only limited success as only a small amount of Factor VIII could be assimilated in this way*" and he suffered joint damage.[206] The witness was later treated at other Haemophilia Centres.

Sunderland

47. According to Dr Goff:[207]

> "*No treatment was given to any cases of hereditary bleeding orders. Any acquired bleeding disorders which were usually complications of other disease or of treatment regimes, were always treated in Sunderland with platelets, FFP, cryoprecipitate, as necessary…*"

[200] HCDO0001933 p. 2
[201] HCDO0002030
[202] HCDO0002030
[203] HCDO0000308_019. The Annual Returns for 1987 are at HCDO0002116, 1998 are at HCDO0002209, and 1989 are at HCDO0002302 (all signed by Dr Chandler).
[204] WITN1721001 para 4
[205] WITN1721001 para 5
[206] WITN1721001 para 5
[207] WITN5423002 para 1.4

48. Dr Goff stated that he was "*not aware of any factor concentrates being administered in Sunderland to any category of patient…*"[208]

49. According to limited information available to the Inquiry, it appears that:

    a. 1976: No blood products were used at Sunderland.[209]

    b. 1979: To treat 1 patient with haemophilia A, Sunderland used 6 bottles / 1,320 units of NHS factor VIII.[210]

    c. 1980: To treat 1 patient with von Willebrand's disease, Sunderland used 490 units of NHS factor VIII in hospital.[211] To treat 1 patient with haemophilia B, Sunderland used 2 bags of fresh frozen plasma in hospital.[212]

    d. 1983: No blood products were used at Sunderland.[213]

    e. 1986: No blood products were used at Sunderland.[214]

Whitehaven

50. Dr Whitehead stated that:[215]

> "*Decisions about the selection of blood and blood products were made by me in conjunction with the Regional Blood Transfusion Centre. These decisions were made on clinical grounds, which in turn were dependent upon the clinical presentation of each patient. To my recollection, no commercial or other non-clinical considerations played any part in these decisions.*

[208] WITN5423002 para 2.3
[209] HCDO0000031_002
[210] HCDO0001376
[211] HCDO0001473
[212] HCDO0001473
[213] HCDO0000190_003
[214] HCDO0000295_002
[215] WITN5308001 p. 4

There was no relationship between the Centre and the pharmaceutical companies manufacturing and/or supplying the products. We obtained the products from the Regional Blood Transfusion Centre ('RBTC'). I have (and had) no knowledge as to where the RBTC obtained products and materials.

The products used were Factor VIII, Cryo-precipitate and von Willebrand's Factor, depending upon the clinical picture.

Decisions as to which products were used for individual patients were made by me on clinical grounds, such as the age of the patient and or the severity of their condition. I cannot now recall whether or to what extent patients were involved in that decision or offered a choice."

51. According to limited information available to the Inquiry, it appears that:

a. 1976: To treat 5 patients with haemophilia A, Whitehaven used 367 bottles of cryoprecipitate.[216] It was indicated that products issued to patients through the Haemophilia Centre at RVI Newcastle were not known.[217]

b. 1977: To treat 4 patients with haemophilia A, Whitehaven used 94 bottles / 6,580 units of cryoprecipitate.[218] It was noted that no blood products were supplied for home treatment "*as the home treatment is managed from Newcastle*".[219]

c. 1979: To treat 3 patients with haemophilia A, Whitehaven used 112 bottles / 7,840 units of cryoprecipitate.[220]

[216] HCDO0000102_002 p. 2
[217] HCDO0000102_002 p. 2
[218] HCDO0001218 p. 2
[219] HCDO0001218 p. 6
[220] HCDO0001383 p. 1

d. 1981: It appears from a handwritten note that 2 patients were treated at Whitehaven with cryoprecipitate in 1981.[221]

e. 1985: To treat 1 patient with haemophilia A, Whitehaven used 2 bottles of NHS factor VIII in hospital. To treat 1 patient with von Willebrand's disease, Whitehaven used 8 bottles of cryoprecipitate in hospital.[222]

f. 1986: A letter dated 18 June 1987 from Dr West to Dr Rizza stated that one patient was treated with "*cryoprecipitate 12 units on two occasions*".[223]

g. 1988: To treat 1 patient with haemophilia A, Whitehaven used 2 bottles of Alpha factor VIII (Profilate) in hospital. To treat 1 patient with haemophilia B, Whitehaven used 5 bottles of NHS factor IX in hospital.[224]

Knowledge of risk of hepatitis and response to risk

52. There is limited direct evidence available to the Inquiry regarding the knowledge of risk of hepatitis at the Northern Centres.

53. Dr Deeble stated, "*As a General Haematologist, I knew of the risks of transmitting Hep B… I was never notified that any of my patients had received infected blood*".[225]

54. Dr Goff stated that he kept up to date with relevant scientific and medical developments by attending weekly regional haematology meetings, attending national and international symposia, and reading relevant journal articles.[226] When he began work as a Consultant Haematologist at Sunderland, he stated that there was "*awareness of the risks of hepatitis*" and he knew that blood was screened for hepatitis B.[227] He was exposed to the problem of non A non B hepatitis during his

[221] HCDO0001585
[222] HCDO0001966
[223] HCDO0000293_002
[224] HCDO0002242
[225] WITN5247001 para 3
[226] WITN5423002 para 21
[227] WITN5423002 para 22

year at Sheffield (1977-78).[228] His knowledge was gained through discussion with colleagues.[229]

55. It is apparent that some Directors of the Northern Centres attended various UKHCDO meetings. It is recorded that:

    a. Dr Inglis (Carlisle) attended UKHCDO meetings on 1 October 1968,[230] 5 April 1971,[231] 31 January 1974,[232] 1 November 1974,[233] 18 September 1975,[234] 13 January 1977,[235] and 24 October 1977.[236] Dr O'Brien attended on 17 March 1986.[237] Dr Deeble sent his apologies for the meetings on 13 November 1978, [238] 20-21 November 1979,[239] and 9 October 1981.[240]

    b. Dr Potts (Middlesbrough) attended on 13 January 1977.[241] Dr Harker attended on 24 October 1977,[242] 20-21 November 1979,[243] 9 October 1981,[244] and 13 September 1982.[245] Dr Summerfield attended on 17 October 1983.[246]

    c. Dr Goff (Sunderland) attended on 13 November 1978,[247] and 17 October 1983. [248] In his written statement, Dr Goff stated that he "*attended the meeting of the*

[228] WITN5423002 para 22
[229] WITN5423002 para 23
[230] HCDO0001013
[231] HCDO0001014
[232] CBLA0000187
[233] HCDO0001017
[234] OXUH0003735
[235] PRSE0002268
[236] PRSE0001002
[237] PRSE0001688
[238] HSOC0010549
[239] BPLL0007384
[240] CBLA0001464
[241] PRSE0002268
[242] PRSE0001002
[243] CBLA0001028
[244] CBLA0001464
[245] CBLA0001619
[246] PRSE0004440
[247] HSOC0010549
[248] PRSE0004440

13th of November 1978 as a learning experience to try and keep abreast of current theories and practice".[249]

d. Dr Whitehead (Whitehaven) attended on 18 September 1975,[250] 24 October 1977,[251] and 13 November 1978.[252] Dr West attended on 9 October 1986,[253] and sent his apologies for the meetings on 21 October 1985,[254] 9 October 1989,[255] 7 October 1991,[256] and 1 October 1993.[257] In his written statement, Dr Whitehead confirmed that he was a member of the UK Haemophilia Directors Organisation and was present at the meetings in 1975, 1977 and 1978. However, he had no speaking role and the minutes of the meetings did not prompt any specific recollections on his part in relation to his role at Whitehaven.[258] Dr Whitehead stated that he kept his medical knowledge up to date "*by attending local and national meetings, liaison with the RBTC, and reading the British Medical Journal and the Lancet*".[259]

e. Dr Mustafa (Darlington) attended on 13 January 1977.[260]

56. Dr Summerfield served as a member of the Advisory Committee on the Virological Safety of Blood.[261] The committee was described as "*an expert advisory committee"* and the Terms of Reference included advising the *"Health Departments of the UK on measures to ensure the virological safety of blood...*".[262]

Knowledge of risk of AIDS and response to risk

[249] WITN5423001 para 2
[250] OXUH0003735
[251] PRSE0001002
[252] HSOC0010549
[253] PRSE0004317
[254] PRSE0001638
[255] HCDO0000015_035
[256] HCDO0000491_001
[257] HCDO0000493
[258] WITN5308001
[259] WITN5308001 p. 4
[260] PRSE0002268
[261] PRSE0001865, DHSC0006179_004, DHSC0002497_094, DHSC0002497_094
[262] DHSC0002429_046

57. There is limited direct evidence of the knowledge of risk of AIDS at the Northern Centres.

58. Dr Goff stated that he "*learned of the possibility of HIV infection by transfusion by journal reading and attendance at symposia specifically related to AIDS*".[263]

59. In a letter dated 26 May 1983, Dr Jones wrote an update on AIDS and haemophilia which was circulated to, amongst others: Dr Lillington, Dr Kerr-Gilbert, and Dr Goff at Sunderland District General Hospital; Dr A A Williams, Dr Harker, Dr Oo, and Dr Summersgill at Middlesbrough General Hospital; Mr Banerjee, Dr Elderkin, and Dr O'Brien at Cumberland Infirmary, Carlisle; and Dr Bird, Dr Platt, and Dr M J Williams at West Cumberland Hospital, Whitehaven.[264] After summarising the position in the USA and UK, Dr Jones stated that:[265]

> "*The Haemophilia Reference Centre Directors met in London last week with Peter Hamilton representing Newcastle. At that meeting it was decided that there were no indications for special measures amongst the UK haemophilic population, apart from stressing the need for very small children (under the age of 4) to be treated with cryoprecipitate in preference to factor VIII concentrate wherever possible. As you know this does not represent a change in policy. Naturally careful surveillance of the haemophilic population will continue…*"

60. On 30 November 1984, Dr Jones wrote again to other Centres in the Northern Region (including Dr O'Brien (Carlisle), Dr Chandler (Middlesbrough), Dr Goff (Sunderland), Dr Kay (Sunderland), and Dr Bird (Whitehaven)) about changes in response to the "*recent problems with AIDS and haemophilia*".[266] All commercial products were being changed for heat treated products, presently ordered from Cutter, Alpha and Armour. In particular, "*Patients who attended the meeting here on*

[263] WITN5423002 para 25
[264] PJON0000057_001
[265] PJON0000057_001 p. 2
[266] PJON0000067_001

Wednesday were told that they should use up their present stocks and that the switch would be made when they returned for new supplies for their home therapy programmes". Meanwhile, Centres holding commercial concentrate in stock should exchange it.

61. In a further letter dated 4 March 1986, Dr Jones wrote to physicians in the Northern Region (including Dr West (Whitehaven), Dr O'Brien (Carlisle), Dr Finney (North Tees General Hospital), Dr Goff (Sunderland), Dr Hamilton (RVI, Newcastle), Dr Bird (Whitehaven), Dr Chandler, (Middlesbrough), Dr Kay (Sunderland), Dr Browning and Dr Collins (Newcastle BTS)) suggesting that:

> "*…no commercial concentrate, of whatever make, is given to anti-HTLVIII sero-negative patients. I am thinking particularly of haemophiliac children, mildly affected patients, carriers and women with von Willebrand's disease. Although the evidence is by no means firm I do not think that we can afford to wait… for the epidemiological studies on the safety of all the heat-treated products. My personal preference would be to use anti-HTLVIII tested cryoprecipitate from the Northern Regional Blood Transfusion Service as first choice for the factor VIII deficient patients, and similarly tested fresh frozen plasma for the factor IX deficient patients, provided that the bleeds are minor. Second choice would be the NHS heat treated 8Y product or the NHS heat treated 9*".[267]

Testing patients for HTLVIII and informing them of diagnosis

62. In a letter dated 11 September 1985 to Dr Hargreaves, Dr Smith of West Cumberland Hospital described the handling of specimens in the laboratory and procedures for HTLVIII testing: "*When a specimen arrives with a request for HTLV III antibody test, that specimen will be sent to the PHLS in Newcastle for testing, in compliance with the recommendations contained in the insert to the Communicable Disease Report of*

[267] PJON0000130_001

August 23rd 1985".[268] The letter went on to state that in relation to haematology: "*As a percentage of haemophiliacs will be HTLV III antibody positive, it would be highly desirable if the hospital "stickers" of such patients could bear this information*".[269]

63. In a letter dated 6 October 1987, Dr Chandler of Middlesbrough General Hospital wrote to Dr Brakerbury at the Middlesbrough A & E Department regarding a patient with Christmas disease who attended the Casualty Department and the risk of HIV infection to the healthcare worker.[270] The letter stated that:

> "*At the time of his referral to Casualty he was believed to be HIV antibody negative, although he was obviously in a high risk group. It has subsequently become apparent that he sero-converted between his last test and late September 1987. Whilst I would hope that the Casualty Officer took all precautions, I think it would be sensible to arrange for him/her to be counselled and to provide a sample as a baseline for HIV antibody testing*."

64. A Short Term Programme for 1988/89 for Sunderland Health Authority set out the local provision for "*AIDS Testing, Counselling and Training*":[271]

> "*<u>AIDS Testing, Counselling and Training</u>*
> *The District has established a local facility for testing for AIDS because of the delays in securing reports from the PHLS. The take up of this facility is such that additional revenue support is required. Similarly, the availability of testing facilities emphasises the need for an extension to the counselling service available in the Department of Genito-Urinary medicine. The staff training initiative mounted within the District has also highlighted the need for a small increase in the resources available within the Infection Control service. The total cost of the above on a full year basis will be £15,000*."

[268] DHSC0003893_128
[269] DHSC0003893_128 p. 2
[270] GMCO0000041_009
[271] TYWE0000367

Numbers infected with HIV

65. In a "*Report to RHA and DHA*" dated October 1985, Dr Jones described the situation in the Northern Region at that time:[272]

> "*The impact of AIDS*
>
> *Details of how AIDS and HTLV III disease are affecting the haemophilic population of the Northern Region have been published (British Medical Journal 14th September 1985, 291, 695-699. The summary of this paper was as follows:*
>
> *One hundred and forty three multitransfused patients with hereditary haemostatic disorders were examined for evidence of disease related to the acquired immune deficiency syndrome (AIDS). Ninety nine patients with severe haemophilia A were tested for anti-HTLV III and 76 were found to be positive. All except one of these seropositive patients had received commercial factor VIII concentrate at some time. Eighteen patients with haemophilia B were tested and all were anti-HTLV III negative. Three out of 36 sexual partners of patients with haemophilia A positive for anti-HTLV III were also seropositive. One, who had recently received blood transfusions, had AIDS with pneumocystis carinii pneumonia. Three patients with severe haemophilia A died from AIDS. A further 30 haemophiliacs had AIDS related complex or lymphadenopathy that could be related to HTLV III infection. There was a significant correlation between lymphadenopathy and anti-HTLV III seropositivity. No evidence of casual spread of AIDS was found since all 68 health care staff tested were anti-HTLV III negative, including three surgeons who regularly worked with patients positive for anti-HTLV III.*
>
> *The resources devoted to counselling and laboratory support in centres treating people at risk and their families need to be urgently reassessed.*"

[272] PJON0000101_001 pp. 4-5

66. By August 1987, there had been 25 cases of AIDS reported in the Northern Region and 20 deaths reported to the CDSC (Communicable Disease Surveillance Centre).[273] The Northern Regional Health Authority produced a "*Report on the Health Service Response in the Northern Region*" in December 1988.[274]

67. A "*Report for Sunderland Health Authority for the year 1 April 1994 – 31 March 1995*" stated that: [275]

> "*In the period between 1985 and March 31st 1994 a total of 29 Sunderland residents were known to have been infected with the HIV virus. Some attended services in Sunderland and some in Newcastle.*
>
> *There were a small number of residents not known to services in Sunderland but attending Newcastle as the result of the administration of contaminated blood products some years ago.*"

68. It is not clear from the report precisely how many Sunderland residents had contracted HIV as a result of infected blood products.

69. A Report by Tees Health Authority for 1998/9 indicated that there were no cumulative cases of HIV acquired from the use of blood factor (e.g. haemophiliacs) in that area.[276]

70. No specific data has been provided to the Inquiry by UKHCDO regarding the number of patients infected with HIV via blood products at Carlisle, Darlington, Middlesbrough, Sunderland or Whitehaven.[277]

Testing for HCV

[273] DHSC0025193
[274] DHSC0006210_046
[275] DHSC0044703_019
[276] DHSC0045305_015 p. 22
[277] INQY0000250

71. There is limited evidence available to the Inquiry regarding the testing arrangements for HCV at Carlisle, Darlington, Middlesbrough, Sunderland or Whitehaven.

72. In 2006, an Inquiry witness who had been treated with factor VIII at Carlisle and Newcastle noticed that the whites of his eyes had turned from white to yellow.[278] He contacted his doctor who told him that his blood tests showed that he had mild hepatitis C. He does not believe that he was treated or tested without his knowledge or consent.[279] At the time, his doctor led him to believe that it was not a serious infection and that he "*would just get over it*".[280] The witness does not believe that he was given adequate information to help him understand and manage the infection.[281] He was not given any information from his doctor about the risks of others being infected as a result of the infection.[282] The witness was later referred to Carlisle Infirmary for treatment.[283]

Treatment arrangements for HIV and HCV patients

73. There is limited evidence available regarding treatment for HIV and HCV at Carlisle, Darlington, Middlesbrough, Sunderland or Whitehaven.

74. In January 1985, it was recommended that, if possible, all patients with AIDS or suspected AIDS in the Northern Region should "*only be admitted to the Royal Infirmary or Sunderland District General Hospital*".[284] On 19 March 1985, the District Management Team of Sunderland Health Authority noted that "*the local procedure for dealing with patients with suspected A.I.D.S. which had been prepared by the District Control of Infection Advisory Committee had been circulated to all relevant staff, and that it was also being made available to all General Practitioners*".[285] A "*Draft Policy for the Prevention, Control and Treatment of the Acquired Immune*

[278] WITN2283001 para 6
[279] WITN2283001 para 14
[280] WITN2283001 para 6
[281] WITN2283001 para 8
[282] WITN2283001 para 12
[283] WITN2283001 para 8
[284] TYWE0000380
[285] TYWE0000443 p. 2

Deficiency Syndrome (AIDS) in the Northern Region" was circulated by the Northern Regional Health Authority under cover of letter dated 10 November 1986.[286] This was not specifically directed at Haemophilia Centres. Under cover of letter dated 26 January 1987, the Northern Regional Health Authority circulated a "*Regional Policy for 'Acquired Immune Deficiency Syndrome (AIDS)'*"[287] to local physicians (but again, not specifically directed to Haemophilia Centres). It was proposed that the "*Regional Health Authority will initially identify three centres, in addition to Newcastle Health District, probably Sunderland, Middlesbrough and Carlisle, which will provide in-patient facilities for patients with AIDS*".[288]

75. An Inquiry witness, who contracted hepatitis C after treatment with factor VIII in 1983 and 1988, was referred to Carlisle Infirmary for treatment under the care of Dr Macdonald.[289] He was admitted to hospital where he was surrounded by patients who were mentally ill.[290] The witness discharged himself from hospital and was later referred back to Dr Macdonald.[291] Dr Macdonald prescribed medication in the form of 12 pills a day and believed that the witness had damaged his liver by drinking alcohol to excess.[292] The witness lost confidence in Dr Macdonald and later transferred to Newcastle for treatment where he received a liver transplant[293] and treatment with interferon.[294]

76. Dr Whitehead stated that he "*was not clinically responsible for any patients with Hepatitis or HIV during my time at Whitehaven*".[295]

JENNI RICHARDS QC

ANNABEL LEE

[286] NHBT0072057_002
[287] NHBT0072057_001
[288] NHBT0072057_001 p. 8
[289] WITN2283001 para 16
[290] WITN2283001 para 16
[291] WITN2283001 para 17
[292] WITN2283001 para 17
[293] WITN2283001 para 17
[294] WITN2283001 para 18
[295] WITN5308001 p. 4

Inquiry Counsel Team

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