

SMALLER HAEMOPHILIA CENTRES PRESENTATION
LIVERPOOL ALDER HEY

Directors and status

1. Alder Hey Children's Hospital ("Alder Hey" or "the Centre"), UKHCDO number 065, appears to have been the principal Liverpool site for the treatment of children with bleeding disorders from at least the late 1970s onwards. During the 1970s and 1980s, treatment was sometimes also provided to children at a site on Myrtle Street ("Myrtle Street"). The exact relationship between the two hospitals is not always apparent, but it appears that they were both branches of Royal Liverpool Children's Hospital ("RLCH"), that Alder Hey was the officially designated haemophilia centre and the focus of treatment, and that some patients also attended Myrtle Street.¹ While the focus of this note is Alder Hey, reference is sometimes made to treatment at Myrtle Street.
2. The identity of the Centre's director in the first half of the 1970s is unclear. From the mid-1970s until 1989, the position was held by Dr John Martin. In an August 1975 letter, sent from Myrtle Street, Dr Martin wrote that he had "*now taken over the care of haemophiliacs at this hospital*" [TREL0000166_032].² The focus of Dr Martin's work appears to have been paediatric oncology and he generally referred to himself as a consultant paediatrician or oncologist, rather than a haematologist. Erica Saunders, current director of corporate affairs at Alder Hey, has told the Inquiry that Dr Martin "*established one of the early childhood cancer centres at Alder Hey*" but that he was not a "*specifically trained paediatric haematologist*" [WITN4194006].

¹ Myrtle Street was sometimes referred to as the "*City Branch*" of RLCH [NHBT0083995_022]. Dr Lynne Ball notes that, at least in 1989, laboratory diagnostics took place on two sites, Alder Hey and Myrtle Street, "*the latter serving supra-regional paediatric cardiac surgery, neonatal intensive care and the recently established department of foetal medicine*" [WITN4739001].

² See also the documents referred to below, in particular the Centre's annual returns and Dr Ball's statement.

3. Dr Lynne Ball was the Centre's director from 1989 to 1993 and has provided a statement to the Inquiry [[WITN4739001](#)]. Ms Saunders describes Dr Ball's appointment as being "*in recognition of the developing speciality of Paediatric Haematology*" [[WITN4194006](#)].
4. Dr Paula Bolton-Maggs was director from 1993 to 2003 and has also provided an Inquiry statement [[WITN4160001](#)].³

Relationship with other haemophilia centres

5. As noted in the note on RLH, there is conflicting evidence as to the relationship between Liverpool's main adult haemophilia centre and Alder Hey.
6. Dr Boulton, who was RLH director between 1975 and 1980, has told the Inquiry that, during his time at Liverpool, "*most younger boys were seen by Dr Martin*" at Alder Hey [[WITN3456001](#)].
7. Dr McVerry, who was RLH director from 1980 to 1985, states that he did not treat any children [[WITN3502007](#)]. His evidence is that he had no involvement with Alder Hey and that it is highly unlikely that RLH supplied blood products to it.
8. Dr Ball's evidence is that, prior to her arrival in January 1989, "*products were ordered and supplied by the Royal Liverpool Adult Haemophilia Centre*", and that "*historically Alder Hey received concentrate for acute care by telephoning the on-call Haematologist at the Royal Liverpool Hospital who organised the transfer of the required product for immediate treatment. If subsequent injections were required for an on-going bleed there was no guarantee that the same batch would be supplied as there was no individual reservation of batches per patient*" [[WITN4739001](#)]. Dr Ball also describes how this system subsequently changed.

³ For a 1995 profile of Dr Bolton-Maggs in the Haemophilia Society Bulletin, see [[HSOC0022987](#)].

9. Close links between RLH and Alder Hey are reflected in a January 1988 letter from Dr Bolton-Maggs to Rosemary Spooner regarding Alder Hey's 1986 annual return [[HCDO0000335_007](#)]. Dr Bolton-Maggs explained that she had added brackets around home treatment figures in the return in order to "*indicate that although these patients were on home treatment, they receive their Factor VIII concentrate from the Royal Liverpool Hospital and, therefore, will have been included on their returns*".
10. Professor Hay, who joined RLH in 1987, has explained that that he "*did not have a contract with Alder Hey Hospital. Whilst I did some joint clinics for a little while Dr Paula Bolton Maggs at Alder Hey to help out, those ceased when Dr Lynne Ball was appointed Consultant Haematologist at Alder Hey in late 1988. Previously, the Haemophilia Unit had been the responsibility of Dr John Martin, Consultant Paediatric Oncologist. I never had consultant responsibility at Alder Hey and have no knowledge of their policies*" [[WITN3289039](#)].
11. In an article published in the Haemophilia Society Bulletin in 1990, Professor Hay wrote that haemophilia care in Liverpool had "*traditionally been divided between Alder Hey Children's Hospital and the Royal Liverpool Hospital, the patients graduating from the one to the other in their mid teens*" [[HCDO0000276_001](#)]. See also an October 1991 letter from Professor Hay to the Haemophilia Society, addressing funding and supply issues that had arisen between RLH and Alder Hey [[HSOC0011048](#)].
12. Links between Liverpool and haemophilia centres and hospitals in North Wales, outlined in the note on RLH, included Alder Hey. Some of these are described in the statement of Dr David Edwards, consultant haematologist at Glan Clwyd Hospital from 1982 to 2006 [[WITN5491001](#)]. Dr Edwards explains that, in the 1980s, paediatric cases "*were initially managed by the Paediatricians with outreach Consultants from Alder Hey Hospital in Liverpool*". An Inquiry witness, whose brother was infected with HIV, has also described links between Glan Clwyd Hospital and Alder Hey when treating her haemophilic sons in the late 1980s and early 1990s [[WITN2441001](#)].

13. This relationship also involved RLH. In a June 1988 letter to Miss Spooner, Dr Bolton-Maggs explained that the supplies of a patient on home treatment were from “*Dr Edwards, Haematologist at Glan Clwydd sent from the Royal Liverpool Hospital*” [[HCDO0000335_004](#)].
14. As for the 1990s, Dr Bolton-Maggs has told the Inquiry that she “*organised teaching and outreach across the North West Region and North Wales and a clinic at Glan Clwydd hospital*” [[WITN4160001](#)].

Relationship with Regional Transfusion Centre and regional networks

15. Blood and certain blood products were supplied to Alder Hey by Mersey RTC (also known as Liverpool RTC). For example, a May 1973 document records cryo being set to Alder Hey and Myrtle Street [[DHSC0100026_064](#)]. A number of documents also show blood being issued from the RTC to Alder Hey (and other Liverpool hospitals) in the 1980s (for example [[NHBT0084589](#), [NHBT0084585](#), [NHBT0084577](#) and [NHBT0084563](#)]). The role of the Mersey/Liverpool RTC is addressed in more detail in the note on RLH.
16. In the mid-1970s, “*Liverpool Children’s*” (i.e. Alder Hey) was described as part of the “*Manchester Supraregion*” [[CBLA0000699](#)]. A later list of haemophilia centres – which appears to be from the late 1980s – makes the same point. The extent of Alder Hey’s involvement in the supra-region is unclear. Minutes of its meetings in May 1985 and April 1986 are available, but Dr Martin is not on the list of attendees or apologies for either [[NHBT0096599_043](#) and [NHBT0094580](#)].
17. As with RLH, Alder Hey belonged to a regional group of Mersey and North Wales haematologists. Dr Martin attended one of its meetings in November 1983 [[NHBT0100235_002](#)] and sent his apologies for another in March 1985 [[NHBT0100234](#)] (see also the minutes for a November 1985 meeting [[NHBT0100233](#)]).

Facilities and staffing

18. Staff at Alder Hey in the 1970s and 1980s included the following:

- a. Dr Hall in the 1970s [[DHSC0100026_064](#)].
- b. Dr Robert Carr, a senior registrar who undertook a rotation in Liverpool between August 1983 and July 1991 [[WITN4677001](#)]. This included some time at Alder Hey, though Dr Carr's evidence is that his work related exclusively to children with general haematological conditions and those with leukaemia and lymphoma. He does not remember seeing any patients with bleeding disorders there. Note, however, that Dr Carr is recorded as having met a Cutter representative in August 1986, while at Alder Hey, and as having discussed Koate HT [[BAYP0000008_351](#)].
- c. Dr Ball, who was a senior house officer in paediatrics at Alder Hey between August 1981 and February 1982, before returning as a consultant paediatric haematologist and Centre director in January 1989 [[WITN4739001](#)].
- d. Dr Bolton-Maggs, who spent 12 months at Alder Hey as a rotating senior registrar in 1987-88 [[WITN4160001](#)]. She returned as a locum consultant haematologist from November 1991 to November 1992 before being appointed to a permanent part-time consultant post in December 1992, as well as taking on the role of Centre director from December 1992 to May 2003.
- e. Nursing staff appointed from the late 1980s onwards included Nicola Mackett, Cathy Benfield and Julie Bowman, and there was access to a social worker, John Donnelly, in the 1990s [[WITN4160001](#)].⁴ An Inquiry witness has also referred to Anne Lord as a haemophilia nurse at Alder Hey at in the late 1980s [[WITN3936001](#)].

⁴ See also the references to nursing staff at Alder Hey and co-ordination with RLH in Professor Hay's 1990 article in the Haemophilia Society's Bulletin [[HCDO0000276_001](#)].

19. In a 1986 Haemophilia Society treatment survey, Alder Hey was recorded as being a hospital at which nurses played a major role in treatment [HCDO0000276_032].
20. The minutes of a February 1988 regional haematologist group record that plans were “*afoot to make an appointment of Senior Lecturer in Haematology at the Royal Liverpool Children’s Hospital (Alder Hey and Myrtle Street) ... Cover would normally be provided by the Senior Lecturer at RLH. (However, during the current absence of any haematologist Children’s Hospitals – cover is being provided by the Consultant Haematologist at Whiston Hospital)*” [NHBT0100232].
21. Dr Bolton-Maggs’s recollection is that, when she was a senior registrar in 1987-1988, there was no consultant haematologist at Alder Hey and no specific facilities for patients with bleeding disorders [WITN4160001]. The patients would have “*been seen for acute bleeding problems on the oncology ward and followed in general haematology outpatients.*” A separate haemophilia centre was later developed. Dr Bolton-Maggs states that haemophilia patients “*would have been under the care of Dr. John Martin, consultant oncologist, and additionally managed by rotating senior registrars in haematology, with advice as required from haematology consultants at the Royal Liverpool Hospital.*”
22. Dr Ball has commented critically on the facilities available at Alder Hey upon her return to the Centre in January 1989 [WITN4739001]. She states that in “*stark contrast*” to her experience at Great Ormond Street Hospital, “*the provision of clinical of clinical and laboratory services offered to children with haemophilia especially those with HIV at the time of my appointment was severely compromised.*” There had been “*no investment in laboratory facilities or equipment for a decade*”. Laboratory staff had “*no protective area to prepare contaminated samples prior to and there were no facilities to monitor immunological parameters for affected children.*”
23. Dr Ball adds that there was “*no established treatment centre, no specialist nurse or social worker provision, no outpatient clinics, no immunological monitoring or screening and the majority of children had not received routine vaccination*

against Hepatitis B and there was a paucity of successful home treatment and self-administration programmes.” As a result, “for acute minor bleeds boys accessed the haematology-oncology ward (C3) and were treated with concentrate ordered and supplied ad hoc from the Royal Liverpool Hospital.”

24. Dr Ball describes being informed by the Trust hospital manager that there was no budget to develop additional services. This was despite having written “*an extensive case of need for a second consultant*”, which she submitted to the manager and “*the newly appointed Medical Director, the former consultant in charge of haemophilia care, Dr John Martin.*” Nonetheless, Dr Ball was able to access a regional AIDS fund, set up by central government, which had “*been active for a number of years but not accessed*” by Alder Hey. She states that she obtained funding for a specialist haemophilia nurse and a social worker, as well as computer support and laboratory equipment, and built up regular outpatient clinics for children with coagulation disorders. A parents’ support group was also established and was attended regularly by Dr Ball, the haemophilia sister and a social worker (though without any financial support from the hospital administration).
25. Around 1990, following events described further below, Dr Ball states that a “*Paediatric haemophilia centre was finally established at Alder Hey*”, providing “*a central storage facility for factor replacement, office space for medical, nursing and secretarial staff, a dedicated treatment room where inhaled pentamidine could be safely administered and a counselling rest room for parents and children.*”
26. Erica Saunders has explained that “[*d*]ue to the lack of specifically trained paediatric haematologists [prior to Dr Ball’s arrival], much of the care of children with non-malignant haematological conditions defaulted to clinicians running the malignant service and was provided on the Oncology Ward” [WITN4194006]. She describes the treatment arrangements as having led to children with bleeding disorders “*being exposed to inappropriate treatment and delays in adopting improvements in their management*”.

Numbers of patients registered and treated

Annual returns 1977-1986

27. Alder Hey's annual returns provide the following figures for patients treated and registered in 1978-1986 (excluding 1985, for which the return is missing):

- a. 1978: Alder Hey treated 10 patients with haemophilia A [HCDO0001274].
- b. 1979: 13 patients with haemophilia A were treated [HCDO0001343].
- c. 1980: 16 patients with haemophilia A were treated [HCDO0001439].
The number of registered patients appears to have been: 26 with haemophilia A; one with haemophilia B.
- d. 1981: 12 patients with haemophilia A were treated [HCDO0001541].
The number of registered patients appears to have been: 25 with haemophilia A; one with haemophilia B.
- e. 1982: 19 patients with haemophilia A and one with haemophilia B were treated [HCDO0001639]. The number of registered patients appears to have been: 26 with haemophilia A and one with haemophilia B.
- f. 1983: Alder Hey treated 16 patients with haemophilia A and one with haemophilia B [HCDO0001739]. The number of registered patients appears to have been: 27 with haemophilia A; 4 with haemophilia B; and 5 with von Willebrand's.
- g. 1984: 14 patients with haemophilia A were treated [HCDO0001831].
The number of registered patients appears to have been: 30 with haemophilia A; 4 with haemophilia B; and 5 with von Willebrand's.
- h. 1986: 19 patients with haemophilia A, 3 with haemophilia B and two with von Willebrand's were treated [HCDO0002021]. The number of registered patients appears to have been: around 32 with haemophilia A (the list is unclear); 4 with haemophilia B; and 6 with von Willebrand's.

Treatment policies and blood product usage

Annual returns 1977-1986 and stock records

28. In 1977 Alder Hey treated its haemophilia A patients with 643 packs of cryo [[HCDO0001177](#)]. Its annual return records that other products (whether NHS or commercial concentrates) were supplied by Dr Boulton at Liverpool Royal Infirmary.
29. In 1978 Alder Hey treated its haemophilia A patients with a combination of cryo (48,030 units), NHS factor VIII (the figure is unclear would but would appear to be around 46,000 units) and Factorate (24 bottles – the number of units is not given) [[HCDO0001274](#)]. The return recorded that the Centre had two haemophilia A patients on home therapy, who received 38,490 units of Factorate and 23,054 units of Koate.
30. In 1979 Alder Hey treated its haemophilia A patients with more concentrate than cryo [[HCDO0001343](#)]. It used: 27,790 units of cryo; 37,500 units of NHS factor VIII and 14,000 units of Factorate.
31. In 1980 Alder Hey treated its haemophilia A with 114 packs of cryo, 136 bottles of NHS factor VIII and 268 bottles of Factorate, all in hospital [[HCDO0001439](#)].
32. In 1981 Alder Hey treated its haemophilia patients almost exclusively with concentrate [[HCDO0001541](#)]. It used 4 packs of cryo, 386 bottles of NHS factor VIII and 29 bottles of Factorate, all in hospital. The Centre's annual return also notes that all products for home treatment were supplied by RLH, rather than Alder Hey.
33. In 1982 the Centre treated its haemophilia A patients almost exclusively with concentrate, most of which was commercial [[HCDO0001639](#)]. It used 16 packs of cryo (equating to 1,120 units), 155 bottles of NHS factor VIII (38,750 units)

and 647 bottles of Factorate (161,750 units), all of which was provided in hospital. A haemophilia B patient was treated with NHS factor IX in hospital.

34. In 1983 Alder Hey again treated its haemophilia A patients almost exclusively with concentrate [HCDO0001739]. It used 11 packs of cryo, 218 bottles of NHS factor VIII (noted to equate to 54,500 units of NHS factor VIII) and 749 bottles of Factorate (representing 187,250 units), all in hospital. The return once more noted that home treatment products were not supplied by Alder Hey. The Centre's haemophilia B patient was treated with NHS factor IX (3 bottles, amounting to 1,800 units).

35. In 1984 Alder Hey treated its haemophilia A patients only with concentrate [HCDO0001831]. It used 339 bottles of NHS factor VIII and 352 bottles of Factorate. Home treatment products were supplied by RLH.

36. In 1986 Alder Hey treated its haemophilia A patients only with concentrate [HCDO0002021]. It used: 28,750 units of NHS factor VIII (of which 2,500 units were at home and the remainder in hospital); 14,250 units of Factorate in hospital; and 9,000 of unspecified other human factor VIII. Alder Hey's haemophilia B patients were treated with 16 bottles of NHS factor IX in hospital (said to equate to 9,600 units). The Centre's von Willebrand's patients were treated with Factorate in hospital (750 units), as well as DDAVP.

37. A number of 1980 stock record cards are also available for RLH [LUHT00000024, LUHT00000028, LUHT00000038, LUHT00000016, LUHT00000017, LUHT00000012, LUHT00000033, LUHT00000004, LUHT00000009, LUHT00000001 and LUHT00000031]. These show Alder Hey being supplied with Elstree and Armour concentrate.

Other

38. In an August 1976 letter, the senior house officer to Dr Martin at Myrtle Street noted that a patient had been treated with cryo [TREL0000166_029].

39. Correspondence between Dr Martin and Treloar's regarding a particular patient provides some insight into Dr Martin's approach in the late 1970s.
- a. In a January 1978 letter to Dr Aronstam, Dr Martin recorded that the patient, who had attended during the Christmas holidays, had been treated with cryo at Myrtle Street [TREL0000166_027].
 - b. In April 1978 Dr Martin explained that the patient had been treated with cryo in hospital during the Easter holidays [TREL0000166_026].
 - c. In November 1978 he responded as follows to a letter from Dr Aronstam: "*I would be very happy if he was trained in self-therapy. I am sure if he had not been at Lord Mayor Treloar Hospital we would have trained him in self-therapy now*" [TREL0000166_024].
40. On 21 February 1985 Dr Martin wrote to BPL, in response to a 7 February letter, to request heat-treated factor for VIII for 15 of Alder Hey's patients [BPLL0010612]. He added: "*I should say that we normally receive our factor VIII via the adult centre at the Royal Liverpool Hospital, whose director is Dr. A.McVerry. I am quite happy to continue this way and Dr. McVerry tells me he has already given you a list of his own patients.*"
41. Two non-contemporaneous documents provide additional insight into Alder Hey's treatment policies in the early 1980s. Both are reports regarding a compensation claim on behalf of a patient who had died following infection with HTLV-III at Alder Hey. The first, dated March 1992, is by Dr (later Professor) Savidge, who was director of the centre at St Thomas's in London [DHSC0043164_068]. It includes the following:
- a. The patient was diagnosed with severe haemophilia A at the age of 4 months by Dr Martin.
 - b. He was first treated in March 1982 with commercial factor VIII. There was "*no documentation at that time to indicate that the treatment alternatives with single donor cryoprecipitate or NHS factor VIII concentrates were ever entertained.*"

- c. In 1982 the patient was treated on 32 occasions with Armour concentrate and 5 times with NHS concentrate. In 1983 he received 7 treatments with US concentrates and two with NHS material. In 1984 he was treated 4 times with US product and 4 times with NHS material, including unheated Armour factor VIII on 2 December 1984. He received treatment from a further batch of unheated Armour concentrate on 21 and 22 January 1985. In 1985 the patient was also treated twice with NHS unheated concentrate and on 9 occasions with NHS heat-treated factor VIII.
- d. At other centres, to Dr Savidge's knowledge, much of the unheated batch of Armour used in January 1985 had been "*returned to the manufacturer, who subsequently heated the product in one of their facilities in W. Germany*", with the heated version made available for purchase from 1 February 1985.
- e. The patient began home treatment with concentrate in December 1985.
- f. Although he was seen several times in 1985, the first documented blood sample for HLTV-III testing was taken on 5 August 1985, with a positive result reported on 8 August.
- g. Dr Savidge considered the case to have two notable features. First, there was "*no documentary evidence to suggest that single donor pool cryoprecipitate was ever contemplated in the management of this case, not even when the patient was initially treated.*" Second, there was "*evidence to indicate a defined preference to use U.S. commercial products (45 treatments) over NHS factor VIII concentrate (9 treatments)*" in 1982-1985.
- h. In the late 1970s and early 1980s, the "*majority of U.K. paediatricians treating infants and children with severe haemophilia considered cryoprecipitate obtained from single blood donations to be the therapeutic product of choice, but if not available NHS factor VIII concentrate should be used.*" This was on the basis that cryo had a lower risk of transmitting NANB hepatitis.
- i. Further, "*sufficient amounts of factor VIII necessary to control haemorrhagic symptoms in such small children, were available in only a few single donor bags of cryoprecipitate, providing a safe and highly*

cost-effective approach to use cases.” The side effects occasionally encountered with cryo were “usually easily controllable with antihistamines”. As the patient in this case required treatment in hospital for each bleed, “any perceived additional convenience for using factor VIII concentrates” did not apply.

- j. *The report concluded that the “lack of consideration and disregard of the then current therapeutic recommendations for the treatment of children under the age of 4 years regarding the use of cryoprecipitate in this case was negligent.” The “overwhelming use” of commercial US concentrates in preference to cryo or NHS factor VIII was “remarkable, particularly in a large city such as Liverpool known to have an active BTS with facilities for cryoprecipitate production and regularly supplying plasma to Elstree for fractionation”.*
 - k. *The “lack of a well-defined therapeutic policy regarding preferential use of domestic use of plasma derivatives in children at this time was negligent”.*
 - l. *During “1983 and 1984, both the mass media and the medical press were inundated with reports of AIDS cases in haemophilia and the potential dangers of large donor pool concentrates and by June 1984 ... it was clear the factor VIII concentrates in their then present form, transmitted HTLVIII.”*
 - m. *Further, in light of information and recommendations on heat-treated material in late 1984 and early 1985, the patient’s treatment with two infusions of unheated US concentrate in January 1985 and two infusions of unheated NHS concentrates in March 1985, when heat-treated concentrates were commercially available, “was negligent”.*
42. The second document is a draft report on the same patient by Dr (later Professor) Ludlam, director of the Edinburgh centre [[DHSC0043164_067](#)]. Key parts include:
- a. The patient was first treated at Alder Hey in 1981 with factor VIII (earlier than the 1982 treatment recorded by Dr Savidge). There was no transfusion record in 1981 but it was likely that the treatment was with

Factorate, given that that was the blood product he received throughout the following year. The report records various other times the patient was treated in 1982-1987 and which products were used.

- b. Dr Ludlam noted that the patient's "*haemophilic bleeds clearly required treatment but it would be useful to know of the policy for treating children with severe haemophilia. In Dr. Martin's evidence it is stated that he was aware of the risks of hepatitis transmission by concentrates, that cryoprecipitate was effectively phased out in 1980 and that treatment was advised by the Royal Liverpool Hospital (RLH). It is therefore necessary to know what policy was operated by the RLH.*"
- c. Dr Ludlam added that "*Dr McVerry's evidence does not accord with this*" and asked "*[w]hy was it decided to phase out cryoprecipitate in 1980? Was there a policy about which patients should receive NHS and which commercial concentrate? Why was concentrate purchased from Armour rather than another supplier? The patient could have been treated effectively with cryoprecipitate in the first few years of life whilst receiving treatment as an out-patient. If cryoprecipitate was not available then NHS concentrate would be the most appropriate therapy. In the absence of both these products then commercial should have been used.*"
- d. Dr Martin had stated that he had no recollection of receiving the 24 June 1983 letter from Professor Bloom and Dr Rizza (which contained recommendations for treatment).
- e. Dr Ludlam recorded various missing pieces of information, including when Alder Hey moved to heat-treated product. He noted that "*[n]o mention is made in the case notes, or in Dr. Martin's submission, about what was said either specifically, or in general, about the possibility of virus transmission by blood products*", and that it would be "*useful to know what information was made available to patients or parents.*"

43. Further insight can be gained from two documents, prepared in 1991, reporting on negligence claims on behalf of patients infected with HIV against Mersey Regional Health Authority. The documents, written for the internal use of the defendants in the litigation (and possibly by the Department of Health's legal

representatives), include assessments of the merits of various cases involving Alder Hey. The first, dated 15 July 1991, includes the following patients [[DHSC0045373_118](#)]:

- a. “JKP 027”, treated exclusively with factor VIII from the age of 2 months in 1984, including Armour concentrate from February 1985 to September 1986 (apart from a single dose of NHS 8Y in January 1986). The patient was noted to have switched to 8Y November 1986. The report considered it to be negligent for concentrate, rather than cryo, to have been used when he was first treated at the end of 1984. If cryo “*was unavailable at this time, then either heat-treated commercial concentrate or unheated NHS concentrate should have been used until such time as NHS heat-treated concentrate became available*”.
- b. “JKP 028”, brother of JKP 027, who was treated exclusively with concentrate from late 1982 when aged 6 months. The patient received commercial material in March 1983, but his records did not otherwise specify batch numbers until December 1984 (when he received NHS concentrate). The patient received 26 ampoules of commercial concentrate between 2 and 19 January 1985, which was probably unheated. The report did not consider treatment with commercial concentrate to have been negligent at the end of 1982, “*when the risks of AIDS were not well appreciated. During the following year however, and particularly after June 1983, when the Haemophilia Reference Centre Directors issued their first recommendations on treatment, the risk should have been recognised: a switch to cryoprecipitate at that time might still have protected the Plaintiff against HIV infection.*” If the patient did receive unheated commercial concentrate in January 1985, that treatment would have been negligent.
- c. “JKP 60”, who was treated at Alder Hey until May 1984 and then from Glynedd Hospital, North Wales, while on home treatment. Treatment “*was evidently with concentrate from an early age*”, though the patient’s Liverpool notes were unavailable. The report considered that “*NHS concentrate should have been preferred to commercial from about mid-*

1983 but supplies were inadequate to adhere entirely to this counsel of perfection”.

- d. “JKP 105”, treated with concentrate from 1978 onwards, which was described by Professor Hardisty as “*in accordance with the policy at Liverpool Children’s Hospital*”. The report concluded that the patient’s HIV infection “*was probably derived from concentrate before the risks were appreciated.*” Switching to cryo in 1983 “*would have deprived the [patient] of the great advantage of home treatment and would probably have been too late in any event.*”

44. A second report, dated 5 September 1991, sets out further assessments of claims against Mersey Regional Health Authority [DHSC0045721_051]. These include:

- a. Updates on attempts to settle the claims by JKP 027 and JKP 028.
- b. “JKP 33”, a mild/moderate haemophiliac whose Alder Hey notes did not identify whether all the treatment he had received was NHS material. A statement from Dr Martin confirmed that “*no distinction was made at Alder Hey Hospital in terms of which product to prefer and the product he would have received would have been that which was available*”. The patient underwent elective surgery in 1983 and, although Dr Martin had said that he “*did his best to discourage the operation, he did not do so in the specific context of the risk of viral infection or the risk of infection of AIDS and the parents were not warned in relation to these aspects*”. The author considered that an earlier conclusion that there had not been negligence would need to be reclassified.
- c. “JKP 35”, a mild haemophiliac treated at Alder Hey with what appeared to be NHS factor VIII in late 1982 and probably with commercial factor VIII in March/July 1983.
- d. “JKP 37”, in relation to whom Professor Hardisty had concluded there was no negligence. Dr Martin had stated that the patient “*had a number of major bleeding incidents and received a substantial amount of concentrate, the majority of it being commercial concentrate. The type*

of concentrate would have been dependant [sic] upon availability and treatment was standard.”

- e. *“JKP 47”, a mild haemophiliac treated at Alder Hey. Investigations into the case with Dr Martin had revealed that the patient had received “commercial Factor VIII in December 1983 for a tooth extraction”, which did not seem to be justified.*
- f. *“JKP 92”, a severe haemophiliac regularly treated at Alder with concentrate, “at least some of it commercial after mid-1983”. The case was “therefore difficult to defend”.*

45. Dr Bolton-Maggs believes that, when she was senior registrar in 1987-1988, *“decisions about treatment products would have been made by staff at the adult centre...I also believe that the concentrates would have been supplied from there”* [WITN4160001]. Her evidence is that desmopressin (i.e. DDAVP) was not used until after 1988-1989. As far as she can recall, cryo was not in use for patients with haemophilia or von Willebrand’s from the time she was at Alder Hey. Over time, DDAVP became the standard treatment for mild haemophilia or certain sub-types of von Willebrand’s disease. She adds that children *“with moderate and severe haemophilia required concentrates”*.

46. Dr Ball’s evidence is that, at the time of her return to Alder Hey in January 1989, there was *“no batch reservation to reduce donor exposure”*, which meant that it was *“difficult to determine what the individual usage per child had been prior to my appointment”* [WITN4739001]. Further, a *“large proportion of the clinical notes of children affected by HIV were on close inspection missing essential treatment and decision-making details.”* As far as Dr Ball could ascertain, *“there were no protocols for the use of alternatives such as cryoprecipitate or DDAVP.”*

47. Dr Ball adds that, to her knowledge, alternatives to concentrates were not offered at Alder Hey prior to January 1989 *“despite the recommendations to treat children with moderate haemophilia with non-life-threatening bleeds with cryoprecipitate.”* She also states that *“factor concentrates were used in mild cases”* before her tenure. Following her arrival, Alder Hey did not use any

different products to those used by the adult unit at RLH, “*except for alternatives as recommended for mid/moderate haemophiliacs with non-life-threatening bleeds.*”

48. An Inquiry witness, whose late son was infected with HIV, has described his treatment at Alder Hey from 1978 [WITN3936001]. She explains that he was always treated on a haematology ward, the “C3 Ward”. Following an examination, Sister Hackett would treat him with factor VIII. The witness recalls that Sister Hackett would always make a note of the batch number used and that, until she was informed that her son was HTLV-III positive in August 1985, he “*displayed no real changes and treatment at Alder Hey remained the same*”. The witness’s recollection is that her son began home treatment – which she administered – in 1985 or 1986. When additional stock was required, her husband would collect it from RLH.
49. Another witness has described Alder Hey’s treatment of her three sons, all of whom had haemophilia A, from the late 1970s [WITN1267001]. Two of them died following infection with HIV and hepatitis C. The youngest, who was born in 1984, was infected with hepatitis C. A treatment record for the witness’s eldest son, who she describes as a moderate haemophiliac with clotting factor of less than 3%, shows that he was treated with Elstree factor VIII in early 1980, followed by Factorate until June 1985 [WITN1267002]. The record for her middle son, who had severe haemophilia A, shows that he was treated with Factorate in the early 1980s, before receiving a mixture of Factorate and Elstree material in 1984-1985 [WITN1267003].
50. Another witness has stated that her father, who had a fibrinogen disorder and was infected with hepatitis C, was treated at Alder Hey as a child before moving to RLH, and received fibrinogen concentrate, cryo and factor VIII [WITN2800001].

Knowledge of risk of hepatitis and response to risk

51. Dr Martin is not recorded as having attended any UKHCDO meetings in the 1970s or 1980s. He would not therefore have been present during discussions of hepatitis risks, though it is likely he received minutes subsequently circulated to directors.
52. A handful of contemporaneous documents relate to hepatitis risks. Some of these show that Alder Hey was involved in UKHCDO hepatitis surveys in the late 1970s and 1980s. A form completed in March 1979 by a registrar to Dr Martin recorded that a patient, who had been treated with Factorate and Koate, had developed hepatitis in April 1978 [[HCDO0000262_057](#)]. A later form reported a patient who had developed hepatitis in 1986 following treatment with Koate [[HCDO0000256_168](#)].
53. In December 1986, Dr Mackie wrote to Cutter regarding an Alder Hey patient he had reported “*some time back*” as having become jaundiced, explaining: “*It now appears that he has Hepatitis A and therefore it is unlikely that his jaundice was in any way related to his factor VIII*” [[BAYP0000009_092](#)]. It is unclear if this is the same patient as that reported to UKHCDO in 1986.
54. In relation to her time at Alder Hey, Dr Ball states that she was “*aware of the acute and chronic nature of hepatitis B and non A non B hepatitis but until reliable serological determination and treatment options were available for hepatitis C only supportive care could be offered*” [[WITN4739001](#)]. She considers that the “*liver dysfunction associated with chronic hepatitis C was initially underestimated in light of the urgency of the HIV problems*”, but that it was later recognised.
55. Dr Bolton Maggs’s evidence is that the “*impact of NANB hepatitis was not fully appreciated for some time. It became apparent that a number of patients with NANB developed evidence of chronic liver damage*” [[WITN4160001](#)].

56. In 1991 Dr Bolton-Maggs reported a case of hepatitis through the UKHCDO adverse events working party [[HCDO0000119_029](#)].

Knowledge of risk of AIDS and response to risk

57. Dr Martin does not appear to have attended any UKHCDO meetings in the 1980s at which AIDS was discussed. As noted above, he is reported to have said, in the early 1990s, that he did not recall receiving the June 1983 UKHCDO letter from Professor Bloom and Dr Rizza regarding treatment in light of AIDS risks [[DHSC0043164_067](#)].

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

58. As with RLH, the arrangements for testing patients for HTLV-III and informing them of their diagnosis is a significant issue in relation to Alder Hey.

59. Dr Ball's evidence is that, after returning to Alder Hey in January 1989, parents of patients informed her that *"they were not counselled before [HTLV-III] testing and received a "positive" outcome by means of a letter addressed to the parents. There was no copy of the letter in any of the case notes but at least two sets of parents had retained the letter"* [[WITN4739001](#)]. She describes being told by parents that they received no personal counselling following the test. Dr Ball recalls that *"[o]ne mother felt a "positive test" was in fact a good outcome and one mother hearing that letters had been sent was so distressed that she was unable to open the letter for months."*

60. Dr Ball's evidence is that, in accordance with a directive given at a 7 October 1991 UKHCDO meeting, all patients were routinely tested for HIV at six monthly intervals when she was director. She adds that her routine testing pre-dated this as she felt it was *"an important screening tool for those boys receiving*

blood products.” To her knowledge, there were no stored samples to identify the point at which Alder Hey patients had seroconverted.

61. As far as Dr Ball can remember, there was no specific policy on informing children and young adults of their HIV positive status during her time at Alder Hey, but “*parents would be informed, and a discussion would be undertaken as to how and when the children would be informed.*” She describes the difficulties parents found in communicating the diagnosis to their children, particularly in the atmosphere of stigmatisation which existed at the time. Dr Ball states that “*[w]ith no treatment and real fears about social stigmatisation and backlash many parents sought to protect their child, I could understand this and worked alongside them to find age appropriate ways to communicate with the children.*”
62. Dr Ball further recalls that there were “*a number of adolescent boys initially unaware of their HIV*”. She describes working “*with the parents to assist them as any sexual activity required a knowledge of transmission risk and prevention.*” Despite the embarrassment and difficulty felt by parents, Dr Ball states: “*We were able to systematically inform the boys and instruct them and this was achieved with the help of the haemophilia sister, unit social worker and adult physician from the sexual health unit at the Royal Liverpool hospital, who was involved in the care of young men with HIV.*”
63. Other evidence supports the conclusion that HTLV-III test results were communicated by letter at Alder Hey in the mid-1980s. For example, in a document prepared in late 1989 or early 1990 during the HIV litigation, setting out RLH’s response to the claim, Professor Hay wrote that “*[s]ome of the patients [at RLH] were informed of their HIV status by post. Parents of children were informed by Alder Hey in a similar way*” [NHBT0085908].
64. Most significantly, contemporaneous evidence is available in a pro-forma letter from Dr Martin, dated 28 August 1985 [DHSC0039536]. The body of the letter merits being set out in full:

“We have now received the results of the special antibody test that we performed on your son as part of the screening programme for all

children with haemophilia and related disorders. I have to tell you that ... does show the presence of HTLVIII antibodies, i.e. he has evidence of antibodies against the virus that is thought to cause AIDS. This does not mean that your son has AIDS but just that he has been exposed to the virus. Most people who are positive for HTLVIII antibody do indeed remain well and never develop features of AIDS. A small minority run a risk of developing this condition in the in the future.

As it is possible that your son may be carrying the virus himself, it is important that precautions are taken in taking blood samples from him and in disposing of any equipment used for blood taking or the giving of replacement factor. We will take the necessary precautions when your son attends hospital. If he is on home treatment you should wear protective gloves when doing a venepuncture, and special care should be taken with the disposal of the needles used. The hospital would provide the gloves and suitable containers for the needles to be placed in after use, and would arrange for these containers to be disposed of.

To enable you to discuss these matters further we have arranged a short seminar on haemophilia and AIDS to endeavour to answer any question you may have. Our Consultant Microbiologist, Dr. Hart, will be present to help deal with the problems...”

65. In addition, the Inquiry has received a number of statements from patients and family members addressing HTLV-III testing at Alder Hey. These include a witness who received an identical letter to that set out above regarding her son [[WITN3936001](#) and [WITN3936003](#)]. The witness explains that she does not remember Dr Martin or any other consultant being involved with her son's care prior to this letter; it was mainly Sister Hackett and other nurses. She was aware that blood samples were regularly being taken for her son but she did not know what they were being used for.

66. The witness adds that, on 4 September 1985, she and her husband attended the seminar on AIDS and haemophilia referred to in Dr Martin's letter. She describes the room as “*full with between 60 and 100 people.*” Dr Martin led the seminar before handing over to Dr Hart. People were “*shouting and asking*

questions, and the meeting ended up being very emotional and hostile. No explanation was provided during the meeting about why this had happened and no one apologised or took blame. I felt as though it was pushed under the carpet that people had been infected with HIV. People left feeling upset and angry about what was raised during the meeting.” She further states that Dr Martin “*was very abrupt and I clearly remember him saying “If you think that you can take this to court, you haven’t got a case”. I thought to myself that we did have a good case... I believe the reason why Dr Martin said this was because he wanted to scare everyone off from pursuing a legal claim.”*

67. Another witness has described being told that two of her sons needed to undergo blood tests at Alder Hey, which “*was just the norm as they were haemophiliacs*”, before receiving a letter informing her they had both been infected with HIV [WITN1267001]. She describes being “*asked to go to Alder Hey the following week. Dr Martin was standing there and he said ‘I don’t want you all coming up here with coughs and colds’. He basically told us that if they had symptoms he didn’t us to bring them to the hospital as not all symptoms were a result of HIV. I was not provided with any information about the virus itself and I was give no information as to the possible routes of transmission or risk of infection to others.*” She finds it “*disgusting*” that she was informed of her sons’ HIV status by letter.

68. A further witness has described how her mother received a letter from Liverpool Children’s Hospital in 1985, advising her that her eight year-old brother had tested positive [WITN1444001]. A week later, her mother was informed by the same hospital by telephone that she had also tested positive. The witness describes being told that the nurse who broke the news by telephone “*was both unsympathetic and insensitive*”. She states that Dr Martin then requested that her mother see him to discuss the results. Dr Martin is said to have advised the witness’s mother “*not to say anything because HIV was receiving plenty of negative media coverage*”, to have told her that she had been infected by an Armour product, though he did not say by which batch, and to have said that her son could have been infected anytime between 1981 and 1985. The witness comments that the “*general attitude of the doctors at this hospital was that of*

resignation....I believe the doctors were waiting for her condition to deteriorate and die. The general approach of the hospital staff towards us was appalling.” She adds that her mother was tested for HIV without her knowledge or consent.

69. Another witness, whose haemophiliac late brother was treated at Myrtle Street, has described how he “*was definitely told verbally on a visit to the hospital. However I am not sure if he received a letter also because he and mum destroyed everything*” [WITN0035001].

Numbers infected with HIV

70. Provisional UKHCDO data available to the Inquiry suggests that 13 patients at Alder Hey were infected with HIV, and that all 13 tested positive in 1985 [INQY0000250].

71. A July 1987 report by Dr Philippa Easterbrook, reviewing the main UK cohorts of HIV positive cases, appears to record 16 cases at Alder Hey [MRCO0000388_188].

72. Dr Ball recall that, in 1989, that there were approximately 12 boys with haemophilia who were HIV positive [WITN4739001]. Her recollection is that, as a proportion of children registered per centre in UK, “*this was one of the highest (if not the highest) proportion of HIV positive haemophiliacs.*” As far she can recall, the cases were “*not limited to those boys who had received multiple units of Factor 8 due to the presence of inhibitors or those with life threatening bleeds.*” All of the 12 patients were under 16 years old.

73. By the end of 1986, at least one patient treated at Alder Hey had died of AIDS [HCDO0000634].

74. The mother of two patients who died of AIDS after having been infected with HIV comments in her statement that at “*Alder Hey it was like a conveyer belt*

of children dying. We would constantly get phone calls from other parents and families telling us that another child had died” [WITN1267001].

Testing for hepatitis C

75. Dr Ball believes that hepatitis C testing at Alder Hey began during Dr Bolton-Maggs’ tenure [WITN4739001]. She cannot recollect *“having any direct involvement other than monitoring liver function test as a surrogate marker”*. She does not recall when hepatitis C testing was introduced but states that it would have been *“subject to the availability of the relevant test being made available by the regional reference laboratory”*. She explains that, shortly after a recommendation to test all haemophiliacs for hepatitis C at a 7 October 1991 UKHCDO meeting, she was absent on maternity leave, *“followed by a period of protracted illness, during which time Dr Bolton Maggs acted as locum and if available would have introduced this as part of the regular screening we already established for other infections.”* Her recollection is that hepatitis C infections were *“discussed at Alder Hey once they became available as patient [sic] and families were being regularly seen and followed up as well as counselled by the Haemophilia Centre staff.”*

76. Dr Bolton-Maggs’s evidence is that children with bleeding disorders at Alder Hey *“would have had their liver function tests and hepatitis status monitored regularly”* [WITN4160001]. She states that, *“once HCV was identified in 1991 and testing became available in 1992, patients would be screened for evidence of seroconversion”*. She further states that the results of any tests performed under her care *“would have been passed to the patients/parents as soon as possible.”*

77. As for information provided for patients who tested positive, Dr Ball states that it *“would have been explained that this could cause chronic liver disease which they would need to be monitored for, and a link was established with a hepatologist at the Royal Liverpool Hospital – Professor Ian Gilmore.”*

Treatment arrangements for HIV and HCV patients

78. Dr Ball's evidence is that, unlike her experience at Great Ormond Street, at Alder Hey *"a number of children at the beginning of 1989 were already beginning to show evident signs of severe immune dysfunction as a result of the virus manifesting in the development of opportunistic infections"* [WITN4739001]. Having consulted with a Professor Levine, she started a number of children on *"PCP prophylaxis as well as treatment with Zidovudine, which was the only viral treatment available at that time."*
79. Dr Ball describes her and others' relationship with hospital management deteriorating as a result of *"one of the boys being acutely admitted to C3 with severe pneumonia as a result of "full-blown AIDS. He was 8 years old."* When they learned that he was HIV positive, parents of children with cancer on the ward became frightened and concerned. Dr Ball describes meeting with these parents alongside the ward senior sister, Doris Hackel, to reassure them *"not only to safety issues, but also to the necessity of the child with a highly immune compromised state being cared for in a ward with expertise and surrounded by staff that he knew and trusted."* The following morning, however, the child was moved to a general paediatric medical ward without consultation with her, under the instructions of the acting senior ward consultant and the medical director (i.e. Dr Martin). Neither Dr Ball nor the nursing staff were able to convince Dr Martin to reverse the decision.
80. From that point, *"all children with haemophilia were no longer to be treated or admitted to ward C3 but would be instead be seen on a general paediatric ward, with nurses who had no experience in the management of immune compromised children or bleeding disorders."* Dr Ball comments: *"The dismay and distress this caused the parents of these boys was in my mind then as it is now as being cruel and unnecessary."*
81. She adds that, around February 1990, the hospital manager met with the patients' parents and *"subsequently agreed to the provision of a dedicated haemophilia unit (which he had previously resisted because of budget*

concerns), training of the nursing staff and the guaranteed continuation of funding for the specialist nurse and social worker. This was how the Paediatric haemophilia centre was finally established at Alder Hey.” Dr Ball explains that she also “helped facilitate additional staff support for the haemophilia unit from the new established McMillan Paediatric Palliative care team”, as towards the end of her tenure “a significant proportion of the children affected were dying from AIDS.”

82. Dr Ball describes the hospital finance department and management as “repeatedly obstructive in advancing the funding for many aspects of treatment and support for children with haemophilia”. She comments that this approach added to the “distress and anger that many parents experienced” in the “time of fear and stigmatisation of the late eighties.” She considers that “Alder Hey failed because there was insufficient staffing and attention to detail by those charged with the care of these patients.”

83. A July 1991 letter from a solicitor representing parents of patients at Alder Hey provides some contemporaneous insight into the issues raised by Dr Ball [DHSC0002459_012]. The letter, which was sent in the context of the HIV litigation and appears to have been directed at the solicitors for the defendant health authorities, summarised an “ongoing dispute” which had led to meetings between the parents and Alder Hey’s general manager. This included that “the children, when requiring in-patient care, are being placed in a general ward together with children with infectious diseases, and no longer, unlike in the past, are being given the support of nursing staff with experience in haemophilia and HIV. Further, they are often passed around “from pillar to post” at times of bed shortage, with no sense of priority...”.

84. The letter added the following with respect to Dr Martin: “I have to say that I am extremely concerned at the conduct ... not only of Mr Butler, but of Dr Martin, the paediatric consultant, who formerly cared for these children and whose position, as Head of Medical Directorships, appears to have drawn him into administrative decisions that had led directly to these complaints. This is particularly distressing for the parents when, of course, it was the clinical decisions of Dr Martin that, in many cases, according to the allegations in the

pleadings, led to the HIV infection. It seems extraordinary that the hospital, seen by the parents as responsible, at least in general terms, for infecting their children, can be so inept at handling patient relations as to bring about the present situation. It is perhaps significant that at no time has Dr Martin offered any personal sympathy or sense of regret to any of the parents.” The solicitor also noted that the parents’ requests for changes were “*fully supported by the consultant haematologist, Dr Ball*”. They had “*no complaint to make against Dr Ball, whose level of care and concern for the children and parents alike ... has been warmly appreciated*”.⁵

85. Erica Saunders, responding to the issues raised in Dr Ball’s statement, sets out her understanding that the “*separation of clinical care of patients with inherited bleeding disorders from the oncology service was partly precipitate by the need to care for a cohort of boys infected with HIV*” [WITN4194006]. She adds: “*The information provided to me, I am afraid, is that this process appears to have happened without appropriate consultation with the families affected or a plan to educate the staff on the General Paediatric ward to which their care was transferred. Members of the Haematology Team welcomed this separation as they felt that care of children with malignant conditions took precedence on the Oncology Unit.*” Ms Saunders comments that she “*cannot now explain these apparent failings*” and that she is unable to explain why, having appointed someone with Dr Ball’s degree of knowledge and specialism, her advice was not initially acted upon by Alder Hey.

86. The Inquiry has also received a statement describing these events from a family member’s perspective. The witness, a mother of two sons infected with HIV and hepatitis C (and a third with hepatitis C), has described how they “*had always been treated on the leukaemia ward; my brother had been treated there and the boys were treated there too. The nurses knew the boys well as they had treated them since the boys were babies, and the boys felt comfortable around them*” [WITN1267001]. One day, after the death of her eldest son in 1989,

⁵ Note that this issue came to the attention of the Department of Health. A July 1991 minute suggested “[o]nly if there was a serious risk of embarrassment for ministers, would we need to consider asking RL to make enquiries thorough [sic] the RHA” [DHSC0003664_136].

“when we arrived at the hospital, they didn’t let us go to our usual ward and eventually demanded that we be treated in the general ward instead.” The witness describes noise on the general ward *“making things unbearable”* for her HIV-positive son, who was suffering with terrible migraines at the time, and adds: *“I was very angry that they moved the boys out of the ward where they were comfortable and familiar with the nurses. This was a cancer ward and was very quiet”*. As with Dr Ball, Erica Saunders has provided a statement responding to this witness’s evidence, apologising on behalf of Alder Hey Children’s NHS Foundation Trust [WITN4194007].

87. As for involving other specialists in the treatment of HIV positive patients, Dr Ball’s evidence is that, in the 1980s, *“there was no specialist in AIDS care for children with haemophilia”*. She *“consulted with other paediatric specialists including haematologist, immunologists as well as pulmonologists, infectious disease specialists, gastroenterologists, dermatologists, neurologists”* and *“actively sought support from specialist caring for young adult HIV patients.”*

88. Dr Bolton-Maggs states that the HIV-infected children at Alder Hey were *“seen regularly and had their immune function monitored”* [WITN4160001]. As for providing treatment and consulting others, her evidence is that:

- a. Advice was sought from clinicians *“including a fungal expert in Manchester, Dr David Denning.”*
- b. Treatment with antiretroviral drugs, AZT and DDI, would have been given as they became available. An *“HIV expert in London at the Westminster Hospital (Brian Gazzard) was consulted for advice.”*

89. Following the introduction of hepatitis C testing, Dr Bolton Maggs’s evidence is that *“[i]n due course reviews as required were set up with an adult hepatologist from the Royal Liverpool Hospital as there was no paediatric experience with HCV management at Alder Hey”* [WITN4160001]. She adds that patients would be monitored and reviewed by the hepatologist, Professor Gilmore. *“No treatment was required. Regular monitoring would be by liver function tests.”* Dr Bolton-Maggs did not have any patients with significant hepatitis.

Other issues

90. Dr Ball states that, when she was first appointed to Alder Hey, “*many of the case notes of HIV infected boys were missing large parts of relevant documentation either within the body of the notes or in the section reserved for correspondence. I was unable to locate these sections nor was I able to determine when or by whom sections had been removed but it wasn’t an isolated case note that was incomplete and this was in stark contrast to the oncology notes kept in the same unit which were by and large complete inclusive of treatment decisions*” [WITN4739001].
91. In the conclusion to her statement, she comments: “*my experiences of trying to provide quality care for haemophilia and HIV infected boys and their families at Alder Hey was the worst period of my 40-year career. The constant refusal by senior hospital management to provide me with even the basic resources went beyond budgetary considerations. No financial or medical reasoning could ever justify the way these families were prevented from accessing the ward and experienced staff who had treated them all of their lives and whom they had trusted to provide continued care when they became infected with HIV.*”
92. In 1987 Myrtle Street was involved in a national “*Coordinated study of Transfusion Transmitted HIV Infection*”, as a result of a patient having been transfused with HIV positive blood in April 1984 [NHBT0083995_020, NHBT0083995_021 and NHBT0083995_022]. In 1992 the patient, who was confirmed as HIV positive, applied for a payment under the HIV Blood or Tissue Transfer scheme [NHBT0083995_012].
93. In late 1990, correspondence took place between the Mersey Regional Transfusion Service and its legal representatives regarding claims from patients infected with hepatitis following blood transfusions. In a December 1990 letter, Dr Martlew noted that screening for hepatitis C antibodies was “*not yet a routine practice in this Country*”, and that he considered one of the claims to be

“yet another incident in which there is liability in the absence of negligence”
[NHBT0083995_017].

94. Alder Hey was involved in the hepatitis C lookback exercise in the mid-1990s: see, for example, documents concerning transfusion with hepatitis C positive blood components in 1985 [NHBT0000045_037] and 1991 [NHBT0085922_006]. A 1995 document, concerning a patient transfused under Dr Martin’s care in 1991, records that Dr Martin did not wish to counsel the patient regarding her transfusion and includes a manuscript note that he did not wish *“anyone else to in the light of her current [illegible] state”* [NHBT0095494_040].

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