Witness Name: Neil Anthony Walker
Statement No: WITN1587001
Exhibits: WITN1587002 - WITN1587009
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NEIL ANTHONY WALKER

I, Neil Anthony Walker will say as follows:-

Section 1. Introduction

1. My name is Neil Anthony Walker and I was born on GRO-C 1971. I live at GRO-C. I am married to Tina and have been since 1999. My wife had 3 children before we met and we now have 4 grandchildren. I have a child myself from a previous relationship called Ashley who was born GRO-C 1991, but I have not seen him since he was 14 years old.

2. I provide this witness statement in response to a request under Rule 9 of the Inquiry Rules 2006 and understand that my wife Tina Walker will also be providing a statement.

3. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

4. I have severe Haemophilia A with a clotting factor of 0 – 0.5% iu/ml.

5. I was given cryoprecipitate between 1971 until May 1978. Between May 1978 and February 1982 I was given cryoprecipitate with the occasional batch of Lister, Kryoglobulin and Cutter. After February 1982 I was exclusively given Factor VIII blood products of Cutter, Lister, Hyland. In 1984 I was moved onto Alpha and in September 1986 I moved onto 8y. All the batch numbers are in my medical records but these differ from those recorded in my UKHCDO records; the batches from April 1980 to January 1984 along with my UKHCDO records for the same period are shown at Exhibit WITN1587002.

6. I was treated at the Sheffield Children's Hospital and then the Derbyshire Children's Hospital. When I was about 16 years I was transferred to the Derby Royal Infirmary (DRI) under the care of Dr Winfield, and then Dr Deirdre Mitchell (nee Dr Deirdre Kay) who was a doctor from Sheffield Hospital. Later at DRI I have been treated by Dr Angela McKernan and Dr Mayne. I have also been seen by Dr Bowmen at Queens Hospital, Nottingham and Dr Christine Lee at the Royal Free Hospital, London for second opinions.

7. I believe that was given infected blood products some time between 1980 to 1985. In a letter from Dr McKernan dated 2 July 1996 he believes that I would have been infected with HIV sometime around 1980, however a letter dated 14 December 2017 states that my HIV 1 was diagnosed in 1983 as seen in Exhibit WITN1587003.

8. I had to go to the hospital every other day when I was on Prophylaxis. I think my parents had had talks about moving off cryoprecipitate treatment, as I was the only Haemophiliac that was not on home treatment, with Dr Winfield and Dr Quereshi. I hated injections and could not do home treatment until I was 16 years old.

9. When I was at the DRI, Dr Mitchell took me off cryoprecipitate and put me on Armour products and then on heat treated Factor VIII. I was not given any

information about it but when my parents raised concerns over the swap, Dr Mitchell reassured them and said that I would be the very last person to get HIV as the Factor VIII was always heat treated and done correctly in the hospital. I was told that in fact I had a much higher risk of problems while I was on cryoprecipitate, as anything bad in the blood would not get through to me once it was heat treated and so any risks were almost redundant with the heat treated products.

10. I remember there was an incident with Dr GRO-D once when I had a bleed and needed treatment so had to go to A&E. One of the nurses said that Dr GRO-D was on the golf course and had asked not to be disturbed. My dad went to find him, as he was on call and dragged him into A&E. However, my dad said that Dr GRO-D was so drunk that he messed up my injections and kept on missing my veins. After this I think that he was struck off. From all this I think got salmonella in my knee and that is why I suffer a knee joint problem to this day.

11. I have been infected with HIV, Hepatitis B and Hepatitis C.

12. From my medical notes, in around October 1984 when I was about 13 years old, my mum became concerned about my health and night sweats and they found out that I was at the tail end of Hepatitis B. It is recoded in my notes that I was Hepatitis B positive on 15 February 1985. I think that I cleared this naturally but it was only around 1995 that GRO-C as seen in the letter from Dr McKernan dated 23 May 1995. Both my notes and the letter are Exhibited at WITN1587004.

13. In around 15 February 1985, when I was 14 years old, I was rushed into DRI with a suspected ruptured appendix. I was put into a separate ward that was in isolation and I was padlocked in. The hospital told my parents that they were going to get me in theatre as soon as possible, but after a while, one of the staff said it was bad they were making me wait and explained that this was due to the fact there was no DRI surgeon was willing to do the operation

due to my HIV, so they had to wait for a surgeon to come up from a London Hospital.

14. My mother found out about my HIV virus from a phone call from Dr Maine. Dr Maine told her that I was HIV positive and I believe my mum passed out on hearing this over the phone.

15. Around this time I had visited a fellow severe Haemophiliac called GRO-A GRO-A who was isolated in a cubical on ward 3 at DRI. I was with my mum and we popped in to see how he was. GRO-A told us that he had contracted HIV. We were gutted for him; he was such a fantastic man and was always smartly dressed in a suit. He had suffered over the years with joint problems leaving him in quite a bad, disabled way. I always felt sorry for him and he always told me not to worry, as the treatment I was getting was much better, so I would not end up like him but unfortunately I did. Two weeks after visiting GRO-A I was admitted to the same room on ward 3 in isolation. A doctor told me that I had HIV or I asked him, but I am unsure which doctor this was. My mum was with me at the time. However, I have memory issues from HIV, so I do not remember this clearly.

16. But, I do remember that my room was horrible as the cleaners were not allowed in, so bed pans and urine bottles were piled up. My bed sheets would get incinerated along with anything else that came into contact with me. Blood samples were taken from me with people having 3 pairs of gloves on and they were shaking and so nervous which just made it harder to take blood and made it more uncomfortable for me. From my UKHCDO medical notes I can see that I was tested for HIV on 28 January 1985 as seen in Exhibit WITN1587005. My mum complained to the hospital and I attach a letter dated 18 February 1995 responding to my mum's complaint at Exhibit WITN1587006.

17. I was never given any information about the transmission of the HIV virus or told to be careful and take extra precautions. I do believe that I should have been given more information and with more concern taken about how I was

told. Dr Mitchell told me to keep everything to myself and not tell anyone about my infections. I was told to tell no one; not even my parents or teachers. I could not just bottle it up though and in about a month, everyone that I spoke to knew of my infections; the police, the ambulance paramedics, everyone. Dr Mitchell did not like that I was so open about my infections but I wanted people to know. I did not want people to get inadvertently infected. This led to me getting bullied at school.

18. A while later, we were invited to a meeting at Derby Royal Infirmary to hear about HIV from Dr Peter Jones. My headmaster at Ecclesbourne Secondary School, Dr Dupey attended this meeting as a guest of ours. Dr Jones told everyone in the room not to inform schools of our HIV status. My headmaster stood up and said that this was not right. Dr Dupey explained who he was and Dr Jones asked how he had been invited and my mother said she had invited him to hear for himself.

19. When I was around 21 years old, I found out about my Hepatitis C infection from a clinic in the Haematology Centre. They had seen it on my records and told me about it but it was the first time I had heard of it. HIV was my main worry. When I found out about I just thought *'Okay, another one'*. I did not really know or understand what Hepatitis C was and I just considered it as another thing to add to the list. I was not really bothered as I had already been given a death sentence with my HIV infection and so another one infection more did not really matter; I just added it on to my ongoing, growing list. I was not told of how to manage the Hepatitis infection. I subsequently found out that my infection was hidden from me for about 2 years.

Section 3. Other Infections

20. I remember receiving a letter from Dr McKernan from DRI and I was called in to talk about vCJD and told that that I could be infected with it. Looking through my medical notes I can see copies of the letters dated 28 November 1997, 19 December 1997 and 23 January 2001. My thoughts were *'mad cows disease, when will it stop?'*

Section 4. Consent

21. I have never known about any tests done on me, or what was actually being tested and therefore could never have given my consent. My mother and I were told by Dr Mitchell before I found out about my HIV status, that no testing would be carried out without our consent.

22. I was never provided any information on what they were testing for.

23. I believe that my first treatment for Hepatitis C in or around 2004 at Queens Hospital, Nottingham was for research purposes, as it was part of a clinical trial. I was removed from this treatment as I was far too ill when taking the treatment.

Section 5. Impact of the Infection

24. Having HIV made me very scared but also resentful towards everything. I started to think of the things that I would miss out on in life and the family that I would never get a chance to have. I blocked many things out at that time as I just did not want to know.

25. I have had many chest infections over the years and also contracted PCP pneumonia over Christmas a few years ago. I had a major potassium shortage that developed in my body and I was on a special drip for about 4 years. Eventually I had this treatment at home. I went through a critical stage for 2 years in 1995 or 1996 where I was bed ridden and had home care. The McFarlane Trust paid for a Porto cabin in the garden of my parent's house to live in. I later converted it to house all my hospital equipment.

26. My Hepatitis C infection caused my bone density to reduce massively. I had a small fall once and from it and I fractured both my tibia and my fibula. I also contracted tendonitis and a fracture just from walking in London for a day. I was initially told that I had cirrhosis of the liver due to my drinking issues from

when I was 16 till 21, however, I was then told that I did not have cirrhosis and so I should not worry as it would be monitored. I recently had a fibro scan and was subsequently told that I had nothing to be concerned about.

27. I had AZT treatment for symptoms of AIDS from about October 1984 until 1994. The AZT treatment made me feel very sick; I was constantly tired and had vomiting and diarrhoea too. My ex-partner's friend's dad knew someone working at the factory where AZT was produced and he told me to stop taking it too because more people were dying from AZT than without taking it.

28. I was also given a treatment called PUVA in or around March 1997, which was effectively like being put in an incubation tent. PUVA was really not good for me as I had significant bleeding, got sores, and my skin was splitting. My GP, Dr Ederven came to see me and said I looked like I had 70% full body burns. Dr Ederven called an ambulance, but they refused to touch me due to my psoriasis and they called burns specialist from Stafford who also refused to take me, so the Derby Ambulance services had to take me to the DRI.

29. Initially I did not get the protease inhibitor treatment for HIV as I believe Dr Mitchell said that I should not have them as I had already been on and off treatment and also she deemed it too expensive. I wanted a second opinion so Dr Mitchell sent me to Dr Bowmen at Queens Hospital, Nottingham around April 1997, but around this time a volunteer called Martin Fox of Derby Body Positive at Derby Drug and Alcohol Service (DDHASS), put me in touch with the AIDS Transmission Project (ATP) in London.

30. ATP referred me to the Royal Free Hospital and DDHASS paid for me to take a private ambulance down to the Royal Free Hospital for a second opinion from Dr Christine Lee on 13 August 1997. I felt that Dr Lee was very reluctant to give me the treatment as she did not want to *'step on the toes'* of Dr Mitchell. I did however manage to get the AZT medication from her. I got a lot of support form DDHASS; more than from the hospital, and so I stopped going to the hospital. I exhibit copies of the letters from ATP dated 6 August 1997 at Exhibit WITN1587007.

31. After I managed to get AZT treatment after Dr Mitchell had refused it, I felt that she changed towards me. When I would go into hospital for my appointments with her, she used to look at me and put my file to the bottom of the pile and make sure I had to wait and be seen last. She treated me very poorly. This was witnessed by either a social worker or my DHASS support volunteer.

32. I was then put on a double therapy treatment for HIV which consisted of Tenofovir (made by Truvada) and Ribavirin. I had to change the combinations I was on about 3 times due to the side effects I was always suffering which were very similar to the side effects I suffered while on AZT. My HIV is now non detectable.

33. My first treatment for Hepatitis C in around 2004 was part of a clinical trial; I was transferred to Queens Hospital in Nottingham for this where I was given 2 treatments of Interferon and Ribavirin which lasted for about 5 weeks. I was virtually at hospital every other day and my haemoglobin was up and down constantly. I became anaemic and I had to have a few blood transfusions; I had no energy. They said that the treatment was too dangerous to continue.

34. My second treatment for Hepatitis C was about 6 years ago in around May 2013 which cleared my Hepatitis C. It was again the same treatments (Interferon and Ribavirin), but this time I stayed on the treatments for about 12 weeks before I was taken off it again due to the treatment making me feel tired and lethargic and also turning me violent and having a break down in hospital. The nurse knew that I was suffering from these symptoms from the treatments. I was violent towards Tina; I did not hit her but I threw and smashed things. I have been told that I will never clear Hepatitis C fully and if it comes back, it will come with a vengeance.

35. My current consultant understands me fully but junior doctors will never listen and always think they know better.

36. I also feel that my infected status affected other treatments such as my dental work. All my dental care was at Sheffield Dental Hospital until I was about 13

or 14. I used to get the ambulance to the train station, got the train and another ambulance would be waiting for me at the platform where I got off, however there are no records of this. We would have dentists come in for talks at the hospital, including one called Dr Quirke who told us that we could not go to a local dentist. My mum asked why and he said it was because he had kids and he did not want any infections. However, he agreed to take me one I moved to Dr Quirke and stayed with him until I was around 19 years old.

37. I begged Dr Quirke to take my teeth out as they were so bad and they were always causing me problems. He took 6 teeth out at his surgery but said that all the roots were connected and so he would have to saw my jawbone down to take them out. I was in serious pain and so he said he could not do it anymore and had to send me to a specialist. He told the surgeon to please not just leave me in the situation like last time, where I was not able to open my mouth due to swelling for 6 weeks.

38. In 2002 I then had all my teeth taken out, but the specialist cut too much of the jaw away and so I am now not able to have dentures. Surgical implants are the other option but they are not covered by the NHS because I have HIV.

39. I have been close to the edge a few times, but then I think about the implications of what I would leave behind. I would not be here today if it were not for my wife Tina. She has been great and she is a fantastic support for me. Without her, this would not have been worth all the suffering. I don't like painkillers, even though I am dependent on them at the moment, but I use them for everyone else that still wants me here.

40. Tina puts on a brave face and she is like my rock. She is very strong and has always been there for me. I had an elbow replacement on 14 February 2013 and have been told that both my arms may have a high risk of being amputated in around 12 years. I am already expecting to be in a wheelchair within the next 2 years due to my Haemophilia.

41. This whole ordeal has destroyed my personal, family and social life, but I have moved on from that now to a degree, although a lot is still locked up inside

me. Tina, the children and grandchildren keep me busy now. They keep me grounded and give me the reason to keep going and fighting. They have all increased the quality of my life. We have taught the grandchildren to be very carful around me and they all know not to touch any blood, medication or any of my Haemophilia equipment.

42. I have no real contact with my dad and I am not really in touch with my mother either. My mother was a nurse but gave it up when I was born. She later went to work in the tax office when I was a bit settled; however, when I needed more care she then left that job to help me. She had already buried my sister, who had died as a baby, and she had the extra stress and worry of me all her life. My dad blamed her for not giving him a healthy son.

43. I want to be positive and I do believe that positivity will have a good impact on my disease. It is very important to stay as happy as possible as I believe your mental state contributes to your physical state. I used to counsel others in the DRI as the doctors and nurses would often ask me to go and speak to specific people that were struggling, because I was strong and managed to cope with everything. I have seen people die in the hospital who were mainly cancer patients.

44. I am worried about not being there for Tina and not being able to support her or the grandchildren. You can never know what life has in store for you around the corner and so that is the hardest part. Steve Dymond's story made me worry about how Su Gorman copes, as does the risk of vCJD.

45. I suffered a lot of stigma due to my infections. It was very bad and I would have people in school threatening to beat me up regularly. Other children would shout at me *'he has got AIDS, run!'* and stayed away from me'.

46. I was also bullied at school by a boy who is a mild Haemophiliac and the son the person in charge of the Haemophilia Society. He did not let anyone with HIV in the group of friends as he said he did not want to be associated with HIV and was worried about being infected.

47. I effectively grew up with the ambulance crew as my dad was an HGV driver so was always away, and my mum did not drive. The paramedics were angry as they were not allowed in with me and everyone who did come in had to wear space suits. I was very active so I always had bruises and cuts.

48. I loved school up until the point I was diagnosed with HIV. I was attending Ecclesbourne Secondary School and it was a very good school where I was doing very well too. I used to get a taxi to and from school as I could not take public transport due to my conditions. Even though I repeatedly had to have time off, I always caught up with my work and I refer to a letter from Dr Winfield dated 14 March 1979 in which he did not think my Haemophilia would interfere with my school or job prospects which I Exhibit at WITN1587008. If I was ever bullied at school I would just hurt myself so an ambulance would come and get me from school.

49. As a result of my infections I kept falling asleep in my lessons and school and was very drowsy. This all happened when I was around 15 years old and the school soon became aware that I was not well. Everyone at the school wanted me to leave but the headmaster always backed me up. He said everyone else can leave before I do. The PTA tried to get me removed from school as some of the parents thought that their children were at risk. The PTA was headed by GRO-D MP who had 2 daughters at my school.

50. However, I had 2 carers in school that would follow me around and wipe up any blood with bleach and always make sure that the risk of the transmission of my infections was kept as low as possible. I was only allowed to stay in school by having these carers. I know the carers were there for a good reason but I just resented them being with me and following me around. They made my time at school horrible. I excluded myself and never really had friends in school. I felt isolated and refused to go out at breaks and dinner as my carers were by my side. I stayed in class waiting to go home. I was so sad and just wanted it to all end.

51. At one point later, my school got in touch and informed me that I was not allowed back in due to my ill health from Hepatitis B. I went in to sit my exams, but I used to get HIV taunts before I went in, which put me off and I could not concentrate on the exam. I felt '*eyes in the back of my head*' and thought of the bullying and taunts that I had suffered since my HIV status. I did not get any 'O' levels.

52. I then turned very rebellious to society. I got involved with the wrong people when I was only 16 years old. I started drinking GRO-C GRO-C and the like. I could not understand why the NHS would not treat me after they gave me the infection in the first place. GRO-C would always comment when he saw me '*aren't you dead yet?*'.

53. Around September 1987 I went to Wilmorton College (which was the site that is now Derby College), where I began studying a 3 year computer programming and technology course. As I had been away from social contact for so long that I did not really know how to interact with people. I was used to special needs and people dying and so getting back to socialising normally was very difficult. I was not used to mixing with people and so it all felt institutionalised. I asked the teacher if I could just take the work home and then I stopped coming in after a year due to my condition as they could not cater for me in the disability section. Also around this time, some people had their cars broken into at college and due to my past, I felt like everyone's eyes were on me. This was another reason I stopped going in to college.

54. I started drinking heavily and was a '*pool hustler*' after this. Once I got the Macfarlane Trust pay-outs I got into a lot of debt too; although I have now cleared everything. I got a Motability car but I had lots of car insurance claims totalling about £27,000 as I lent out my cars and they got damaged. The Macfarlane Trust managed to get this written off on the basis that I never apply for a Mobility car again, unless I paid the outstanding amount in full, and then they would decide.

55. I have been cautioned by the police multiple times for drink driving, even when I have not had a drink for days. I later found out that I have enzymes in my liver that do not break down alcohol properly and so this is why even after days, I have high levels of alcohol in my system. I was banned for driving for a year around 1996.

56. I suffered from work related effects of my illness too. After college I was working at East Midlands Hospital but due to my bleeds, kept having to have time off. I eventually gave up the job as I constantly required time off. I missed this as I was treated as an equal person with needs.

57. I then went to apply for a job at a disabled resource centre. The interview went well and the interviewer told me that the job was mine. However, just before I left, I told him of my Haemophilia and then that I was infected with HIV and Hepatitis and he suddenly stopped the interview and said that he had more people to interview. A few days later he phoned me and told me that there were no jobs there for people like me. He was a triple amputee himself. This experience made me decide not to seek employment.

58. Inevitably this all led to me having financial struggles. I had no security in a job or a steady income and I could only live from the cash I got and the government benefits. It was very difficult.

59. I had a lot of companies offering me loans and as I thought I was going to be dead soon and I did not really care about anything, I just accepted them so they stopped hassling me. I never spent anything I just collected the cheques.

Section 6. Treatment/care/support

60. I think that the GUM clinic at DRI did an assessment and then referred me for counselling. This counselling was done through social services and I saw a psychologist every 2 weeks for about 3 and a half years. This was brilliant for me and really helped. The first time I saw him, I came out and punched the filing cabinet as no one had gone that deep into my head before. I exhibit a

letter dated 26 June 1996 at WITN1587009 and have a further psychologist report which can be made available to the Public Inquiry if they wish.

61. The psychiatrist also did some counselling for my wife Tina too and GRO-C GRO-C

Section 7. Financial Assistance

62. When I was about 16 years old I had £20,000 from the Macfarlane Trust but I blew it all in a few months and got into £12,000 debt. I was buying friends drinks all night and spent money recklessly. I could drive at 16 as I was disabled and couldn't ride a motorbike so it was legal. I bought a new car and did so much work on it that I used up all the money.

63. I think I found out about the Trusts when I was 18 I think as I got a payment them in around 1989. Tudor and John Williams I believe informed me.

64. I was involved in 1991 HIV litigation and I received about £40,000 from this. The Macfarlane Trust also paid for a porta cabin in my parent's garden. However, my first son Ashley, from my previous relationship did not get a payment from the Macfarlane Trust as Ashley was a day late in applying, as be was born on GRO-C 1991. I thought that this was rather harsh.

65. I received monthly payments from the Macfarlane trust of £392 a month until EBISS and this then went to £9,000 every quarter and £382 a month.

66. I received a Skipton Fund stage 1 lump sum of £20,000 and then a stage 2 payment of £24,000.

67. At first the Trusts were brilliant and to apply for money was fine. I told the Macfarlane Trust about 4 years ago that I had problems with damp in my house. They paid for an independent surveyor, and companies quoted me £13,000, which the Trust turned down. Then it went to a '*round robin*' with the Trust. The person on board of the trustees of Macfarlane Trust was the same person that bullied me in school. I appealed their decision and it still got

rejected. I think that it got blocked due to this person. In the end I did the work with my friend, and needed an elbow replacement following this due to the damage I did to it from all the work.

68. However, the Macfarlane Trust did pay towards some work in my house with new doors, windows, a bed and a washing machine, all totalling about £19,500 very recently. However, the Trusts changed in the last few years and it became increasingly difficult to get anything out of them. Now I am struggling to get around in my manual wheelchair.

69. My observations of the Trusts are that the remaining £650,000 in the Macfarlane Trust should have been ring-fenced for us and our widows and families and everyone else that suffered, rather than being transferred to the Terrence Higgins Trust. I need to protect everyone that I am leaving behind and I feel that this should have been taken into consideration as I cannot get any life assurance or protection for my family.

Section 8. Other Issues

70. Thinking back on my life before I met my wife Tina, I never wanted to go down the path I went down. I knew what I was doing was very wrong and out of character for me, being one of the most polite, caring, sensitive type of persons with good manners. My HIV sentence turned me into wanting to payback what had happened and with no understanding why this could happen to everybody. I lost so many friends, it scared me so much and growing up I found it very hard to cope.

71. Giving this statement made me think how bad I really was and I regret it so much. I was living with a buzz from doing wrong and the danger of being caught. But what could they do to me as I had already been given a death sentence with HIV and Hepatitis C. I was like a ticking time bomb. Thankfully my life changed for the better and I have one fantastic loving caring wife, our kids and grandchildren. They get me through these difficult times.

72. I would like some closure and some truth from the Inquiry. I want the people responsible to get what they deserve. Too many people have died. It makes me think how many people were classed as pups and infected as part of a clinical trial. I want security for my family and assurance that another disaster like this will never be allowed to happen.

73. My current consultant, Dr McKernan, has my full trust, like Mr M Espag, my upper body surgeon who replaced my elbow. The present team is fantastic and needs replicating in other hospitals. I understand that mistakes are made and I do not hold Dr McKernan responsible for this, rather I hold the government and the Blood Service responsible.

Anonymity

74. I do not wish to remain anonymous.

NAY [illegible] I wish to

75. I ~~am unsure whether to~~ provide oral evidence to the Inquiry.

WAO

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed. GRO-C ....

Dated........30/5/2019..........................

16

Medical Chronology

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the statement)

Medical Chronology

19/7/1971	diagnosed with Haemophilia A. given first cryoprecipitate
31/5/1978	Lister AHG x 240 units Batch No HL1410
1/6/1978	Lister AHG x 240 units Batch No HL1410, then went back to cryo
27/3/1980	letter from Sheffield Children's Hospital to Dr Winfield. His hepatitis B serology is negative (AgAb by HIA and AG by RIA – Ab not done by this technique)
7/8/1980	whilst on holiday Kryobulin 238 units Batch No 09MO7679
6/11/1981	Lister HLA2858 3 x 245 units
13/3/1982	Lister HLB2899 4 x 255 units
14/3/1982	Lister HLB2899 2 x 255 units
15/3/1982	500 units NC8347 Cutter
5/4/1982	last cryo. After this moved on to Cutter, Lister, Hyland and in 1984 Alpha, then Sept 1986 onto 8Y
1983	HIV 1 infection diagnosed
22/6/1984	Feeling unwell, mother describes a reaction following infection. Good appetite, feeling generally little bit unwell. Abdominal pain. O?E OLN, liver smooth palpable 2 cm, spleen palpal 3 cm
28/1/1985	date first HIV positive UKHCDO – 07 Patient HIV data
15/2/1985	14 yr. old haemophiliac. c/o abdo pain. central + upper abdo... had hepatitis in Oct 1984. not right since. occasional episodes of abdo pain. has c/o loss of appetite & taste since. Pain began – 36 hours or so ago, more or less persistent, perhaps increasing this evening. NB he is HTLVIII +ve (carrier) therefore to single room W3 overnight, signed Registrar to Dr Thereaux.
Oct 1989	started AZT. Took intermittently (and there are more than a few comments in the notes between then and 1994 about his poor compliance – per Dr McKernan letter 22/4/1997)

Nov 1990	septic arthritis in R knee. Salmonella & Steph 9. required prolonged antibiotic treatment and orthopaedic drainage
15/1/1991	letter Dr Mayne to GP. I fear that his HIV infection is progressing since his CD4 lymphocytes are down to only 0.18 x 10 3/ul
10/3/1992	apparently has not been taking AZT regularly. only takes it when he feels unwell. ... He has agreed to take all this tablets including AZT on a regular basis
21/1/1993	getting over shingles. cough started up again. GRO-C
13/3/1994	RTA yesterday. HIV+ Hep B+. painful R knee. Girlfriend left him but Neil still sees his son Ashley at weekends. Has his own flat.
April 1994	R pneumothorax. Pneumococcal chest infection. Pneumonia. Pneumococcal septicaemia
2/11/1994	developed abscesses. also PUVA therapy for his skin
23/5/1995	letter Dr McKernan to GP. As you know he is a severe haemophiliac who is HIV and Hepatitis C and Hepatitis B antigen positive. He spontaneously brought up the topic of the possibility of his family contracting Hepatitis B as the result of being in close contact. Neil has been Hep B positive for some years now and I was very reassuring about the low possibility of this happening and also completely ruled out the possibility of his family contracting HIV or Hep C from casual contact. I subsequently discussion this Dr Bullock, Consultant Microbiologist, who felt that Neil's family should be vaccinated against Hep B and I will arrange through Joe Clark, our social worker, to discuss this topic with them. I would, however like to play this down as much as possible, as I think: a) the risks are small and b) this may be closing the stable door after the horse has bolted. Neil has clearly come to terms with his death and in fact seems to be embracing it. He has a living will form to fill in which he has not yet filled in and he is arranging a prepayment policy for his funeral. In the meantime, he seems to be enjoying life...
11/7/1995	allergies: aspirin, cryoprecipitate. Smokes 40 cigarettes day. Drinks 6-7 pints/day + few shorts. Lives in porta cabin in back of Mum & Dad's house.
12/7/1995	extensive oral candidiasis, extensive psoriasis
2/8/1995	discussion with mother & stepfather. Suggest both should be vaccinated (Hep B)
6/8/1995	Clinical Psychology report Simon Thomas, Clinical Psychologist (HIV/AIDS and Psychotherapy). It is important to note that the tests on which these impairments have been most clearly observed – Digit

Symbol, Trail Making Test and the Dual Attention Test – are those that are known to be highly sensitive to early cognitive changes in HIV-related brain impairment.... In summary the two assessments completed to date would suggest the presence of a mild cognitive impairment with early HIV infection of the CVS. The fact that there has been minimal evidence of further deterioration in these areas of function suggest a pattern of slow progression, however it is recommended that further testing in carried out in six months time.

8/8/1995 saw Simon Thomas Clinical Psychologist, re his worries re himself and his mother

13/8/1995 very anxious due to his diagnosis and social problems that it causes him. Drinks heavily for 2 years + +. Dishevelled. Alcoholic ? Anxiety and poor coping – patient readily accepts this. Sleeping tabs tonight. Monitor. Sounds like he's got all the social/ psychological input he's going to get already – a difficult problem for him / us to solve

1/9/1995 letter Dr McKernan to GP – I would therefore be most grateful if you could arrange to vaccinate Neil's brother, his mother and his stepfather against hepatitis B

31/10/1995 Dr McKernan. All investigations suggest his liver is inflamed. Neil has 4 contributory factors to the disease – HBV, HCV, HIV + heavy drinking (10-12 pints + cocktails/day). We discussed Interferon but Neil is not particularly keen on this and in view of his v low CD4 counts and v heavy drinking I doubt it is appropriate

23/1/1996 abscess on right shoulder, bronchiectasis

5/2/1996 letter from Pinders Solicitors regarding GRO-C GRO-C

22/2/1996 letter Dr McKernan to Dr Windebank, Dept of Cardio-Thoracic Measurement DRI. I would be most grateful if you could see Neil Walker who is a severe haemophiliac with AIDs. He is also Hep B and Hep C positive. One of the features of his AIDS is that he gets recurrent bacterial chest infections due to haemophilus influenza and also has chronic sinusitis. He has a persistent cough of a lot of sputum and this bothers him, particularly at night. I suspect he now has bronchiectasis

24/4/1996 letter from Macfarlane Trust to Dr Mitchell asking her to fill in an anonymous case summary as Neil has made a request

4/6/1996 saw Simon Thomas, Clinical Psychologist. Reports feeling down about having to be in hospital at such frequent intervals. Discussed issues relating to him having to adjust to impact on his lifestyle of his recent health downturn. Also concerns re how his health is affecting his weekend contact with his son Ashley. We also discussed resuming more regular weekly contact to help him adjust to this stage of his

	illness and to discuss feelings that may come up in relation to him beginning again to make a Memory Box for his son.
2/7/1996	letter from Dr McKernan to whom it may concern. Mr Walker acquired AIDS, hepatitis B and C from the blood products that he received as part of the treatment for haemophilia prior to 1985... Mr Walker would have been infected with HIV sometime around 1980; this means it is now approximately 16 years since he acquired the HIV virus... It is very difficult t predict how long Mr Walker has to live. However, the length of time he has had the HIV virus, the very low CD4 count and the recent pattern of severe infections suggest that his time is limited.
27/2/1997	home care by District Nurse, Liaison Nurse, Social Worker & Psychologist
4/3/1997	dermatitis referral for long standing psoriasis – v extensive and intensely itchy
14/3/1997	PUVA treatment for extensive psoriasis (26 years old) 2 times/week
9/4/1997	PUVA to stop as Neil has reacted, skin very red and sore. Abscess on leg. They would like Neil to be seen at Royal Free for general assessment a& consideration of Protease Inhibitors
15/4/1997	problems – pyrexia, abscesses, oedema, chest – feels more difficulty breathing, oral candida, difficulty passing urine, eyes, viral load, skin – v inflamed & tender
22/4/1997	letter Dr McKernan to Dr Bowman. He was found to be HIV positive in 1985 but would have acquired this from Factor VIII concentrate sometime in the late 1970s, early 1980s.... Several weeks ago he asked me about proteinase inhibitors. I responded positively about this but realise that there may be a funding problem.
23/4/1997	I have arranged for Dr Bowman of Nott's City Hospital to see Neil. We discussed Dr Bowman possible strategies: viral load, AZT + 3TC, viral load to test compliance... Neil agreed that when I first came to DRI (March 95) we discussed using AZT + ? But he didn't want to then as he had been on AZT previously but had often not taken it. He is now willing to try anti retrovirals again
25/4/1997	letter Dr Bowman to Dr McKernan. Neil told me that he had booked to go down to the Royal Free Hospital in London for HIV treatment.
30/4/1997	to start combination of AZT + 3TC today
8/5/1997	Nil has ?, diahorrea and an itchy rash. These may be side effects of the AZT + 3TC
22/7/1997	day case for blood transfusion

24/7/1997	Plan: stop AZT + 3TC
5/9/1997	letter Dr McKernan to Dr Lee - stopped AZT as it depressed his white count profoundly (neutrophils <0.5) + 3TC as he developed quite a marked rash which recurred on re-exposure. I have not seen Neil since his visit to you but I have spoken to him ... and he told me that he had stopped taking DDI as he couldn't tolerate it
19/9/1997	letter Dr Lee to Dr McKernan. Today we have started him on a combination of saquinavir and ritonavir
13/8/1997	first seen at RFH by Dr Christine Lee
26/9/1997	Neil authorised release of information to MFT. Letter Dr McKernan to MFT strongly supporting his request for funding to go on holiday
23/10/1997	letter Dr Lee to Dr McKernan. tolerating saquinavir and ritonavir well
28/11/1997	first letter Dr McKernan to Neil re vCJD
5/12/1997	Discussed vCJD. Neil has received my letter and the haemophilia society letter. Neil is very unconcerned
19/12/1997	second letter Dr McKernan to Neil re vCJD
23/12/1997	Discussion re vCJD. Neil has read my second letter. I have explained the way American plasma is collected and the viral inactivation techniques that are used. No plasma derived product is completely safe but there is no reason to find American plasma FVIII is less safe virally than British. The UKHCDO say that as regards the vCJD American Plasma is safer. Neil is agreeable to change to @nate but will use up his replinate home treatment
24/12/1997	Dr McKernan memo. There are several vials of Replinate Batch Non FHF4632 in Ward 10 refrigerator which Neil Walker has been exposed to – this can be used for him if he presents to Ward 10. (also comments on other patients)
13/1/1998	Letter Dr Freeman, Consultant Gastroenterologist Derby City General Hospital to Dr McKernan. Thank you for asking us to see Neil. He seems to have slipped through the net... He tells me he was jaundiced about 12 years ago when his hepatitis B was diagnosed
12/4/1998	first mention HCV +ve
6/7/1998	HIV viral load undetectable
28/7/1998	letter Dr McKernan to GP. He has had a liver biopsy by Dr Freeman which showed a Nodel score of 4.

28/8/1998	letter Dr Freeman to Dr McKernan. His latest biopsy shows he has a Knodell score of 4 and therefore does not warrant intervention with Interferon
17/11/1998	unable to tolerate liquid form of Ritonovin. b/w Prof Lee Royal Free – suggests Indinovir + saquinavir
24/11/1998	phone call from Neil to express concern over headaches & nausea & light headedness he has been experiencing since commencing Indinovir. d/w Dr Mitchell, leave off Indinovir and see Dr McKernan 2/12/1998
14/4/1999	recurrence of oropharyngeal candidiasis (first noted Aug 1992). Referred to Dr Dhar
12/11/2000	admitted via A&E GRO-C knee injury
23/1/2001	third letter Dr McKernan vCJD. A blood donor has recently been found to have vCJD and plasma donated I 1996 and 1997 was used to make clotting factor concentrates. The plasma from this donor will have been a small volume in a large pool of plasma from other donors. The products made were Replenate, BPL 8Y, Releninine-VF and ATIII
25/4/2002	letter Dr Quirke to Dept Oral & Maxillofacial Surgeon DRI. Neil has haemophilia and became infected with HIV when he was in his teens, by a contaminated batch of cryoprecipitate.
25/7/2002	letter Satnam Sira, SHO Maxillofacial Surgery to Dr McKernan. Your patient was referred to me by Mr Quirke, Senior Community Dentist. Unfortunately after years of dental treatment Mr Walker's dentition is now in such a state that he requires a full dental clearance.
25/9/2002	dental clearance
13/2/2003	generally tolerating Interferon therapy with minimal side-effects. Finished course July 2003
29/1/2004	letter Dr McKernan to GP. He tells me that, although, the initially Interferon and Ribavirin worked, his PCR has now become positive again. (responder / relapse to pegylated Interferon and Ribavirin 2004 – 12 months). treatment at Nottingham
30/1/2004	letter Dr Freeman to GP. You will recall he has been in the Roche PEGylated Interferon Ribavirin trial at Queen's Medical Centre (QMC) but unfortunately he has not sero converted
20/4/2005	letter Dr McKernan to GP. He had a pegulated Interferon and Ribavirin. He asked me about implants for his teeth, he had a dental clearance

	several years ago and several attempts at fitting dentures have failed. He has been advised that he requires implants but these are very expensive. I am making some enquiries as regards funding.
29/7/2005	Dr McKernan referral to clinical psychologist [redacted] [redacted] Neil's assessment of the situation is that his wife is very concerned about his HIV status [redacted] This in turn makes him depressed.
2/2/2006	referred because of hypertension
21/7/2006	letter Simon Thomas, discharged Neil as DNA
Feb 2010	switched from Combivir / Nevirapine to Truvada / Nevirapine to better cover the Hep B
2011	liver biopsy – stage 2/3 fibrosis (mild – moderate)
21/5/2013	first dose Interferon and Ribavirin for his hepatitis C
16/9/2013	15 weeks into treatment. Recurrences in his mouth, weight loss and a decreased appetite, however at present he is keen to persist with the treatment.
13/2/2014	elbow operation.
7/4/2014	I am pleased to see that his Hepatitis C RNA has remained undetectable at 12 weeks post treatment
7/7/2014	I note that his Hepatitis C RNA is still undetectable 6 months post treatment
27/10/2014	he continues to have an undetectable Hepatitis C viral load to be consistent with successful treatment
16/2/2015	he has been discharged from the Hepatology service as his Hepatitis C has now cleared. We will continue to monitor him from a Hepatitis B point of view with six-monthly Hepatitis DNA and yearly Hepatitis B surface antigen testing
20/1/2016	I note Neil has had some upper abdominal pain and was due to have a gastroscopy which was cancelled due to the risk of variant CJD, but hopefully this will be booked again soon.
Oct 2016	foot fusion – failed
Sept 2017	further ankle operation
2/6/2018	elbow replacement (cancelled due to being unwell, but planned for June/July 2019)