

Witness Name: Stephen John Nicholls

Statement No: WITN1432001

Exhibits: WITN1432002-9

Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF STEPHEN JOHN NICHOLLS

I, STEPHEN JOHN NICHOLLS will say as follows:-

Section 1. Introduction

1. My name is Stephen John Nicholls, DOB [GRO-C] 1967. I live at [GRO-C] [GRO-C] Surrey, [GRO-C]. I am married with 2 children and 2 step-children.
2. 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

3. I was born with severe Haemophilia B and was diagnosed in or about 1968. At that time my family lived in Portsmouth. My father was serving in the Royal Navy and my Mother worked part time. I have one sister who is two years my junior.

4. I didn't encounter too many serious problems with my haemophilia until I was around four years of age, at which point my bleeds became more regular and severe.
5. I was first treated with factor nine concentrate when I was around 6 years old. Prior to this I was treated with cryoprecipitate. I believe at this time the factor 9 was supplied by Oxford. At this point I was put on home treatment and transfusions were administered by my then GP or mother. Records of the reasons for my injections are recorded in my records which were sent to St Mary's Hospital in Portsmouth where I was under the care of Dr O'Brien. These records are now shown to marked "**WITN1432002**".
6. When I was about 7 years old, due to my regular bleeding episodes I was missing lots of schooling and my parents applied for me to attend Treloar's School, which specialised in caring for young people with disabilities including haemophilia. My Father became aware of the school from a friend who was a teacher and had worked there, Their reasoning for this was to gain access to the medical treatment that I required and to try and provide the education without missing school due to bleeding episodes and hospital visits.
7. The main issue they faced was with funding my place. The Royal Navy offered to contribute towards the school fees because my Dad was often away at sea for a year at a time. However, shortly after this it was agreed, the local authority would fund my place at the school.
8. I started attending Treloar's when I was 8 or 9 years old. My records suggest I joined the school in September 1976. There were about 20 children in my year and I still believe that it was the best place for me to go given my haemophilia and the impact that my illness had been having on my education and health.
9. At Treloar's there was always medical treatment immediately available and we were given the treatment as and when we needed it. If I had a bleed I was treated on site and could be back in class an hour later. I was seen by

numerous doctors and consultants but within a few years Dr A Aronstam, became the consultant haematologist, and then Dr M Wassef.

10. The school provided a good standard of education because class sizes were small.

11. When I joined Treloar's the treatment was a mix of cryoprecipitate and freeze dried Factor IX. However, within a year, they moved to just freeze dried factor and I was then taught to administer my treatment myself. This was quite normal – all the boys were taught to do it. There is now shown to me marked **“WITN1432003”** a copy of my treatment record from Treloar's.

12. Around the age of 11 the school really started to push the use of prophylaxis treatment. They encouraged most to be treated regularly with factor (in my case Factor IX) and if they could have you taking prophylaxis every other day then they would. Naturally most of us tried to resist this as we were young boys who wanted to be outside playing instead of having a needles stuck in your arm several times a week, however they remained very insistent and if you hadn't been in for your treatment by 4 pm a nurse would come and find you and take you to the treatment room. Treatment only took about half an hour but we had it so regularly that lots of peoples' veins suffered but this was considered the norm. I wish to stress that at no stage was there ever any mention of the risks or danger involved in having this treatment and any discussions as to the balance of benefit was not mentioned to my parents or myself.

13. The treatment room had about 8 tables in it. When I arrived pre mixed doses would already be out on the tables; each one labelled with a pupil's surname. In the early days if a boy had not turned up for treatment and there was not a syringe ready with your name on it you could simply be given someone else's' dose. There was a particular period of about 4 years where it was very much like a cattle market (one in one out) as we were churned through. The treatment was always pre mixed at that stage. In hindsight we were all unknowingly playing Russian roulette with our young lives.

14. Blood was taken for testing regularly and at least every fortnight it would be taken both pre and post treatment. I was never told why my blood was being taken, and again it was considered the norm.
15. This continued until I was about 15 years old. After that the push to be on prophylaxis slowed and the way in which treatment was organised completely changed. Record keeping was noticeably tighter and you weren't allowed in the treatment room alone without a member of staff. Previously you would just go into the treatment room and give yourself the treatment if you didn't want to wait for the nurse; however they suddenly became incredibly strict. Locks were put on fridges, the treatment was mixed by staff in front of you and a nurse was always present to administer treatment. Detailed records were kept of all treatment and we could no longer administer the treatment ourselves unsupervised.
16. The following year, rumours started circulating in the media about a link between haemophiliacs and AIDs. Overnight Haemophilia became a dirty word.
17. It was around this time that some of my friends at school started showing symptoms of illness that was nothing to do with haemophilia bleeding. It was an incredibly scary time for us. We were young and didn't really know what was happening but seeing my friends suddenly become so unwell so quickly and dramatically was frightening. When people started getting seriously ill and it was clear that death was a possibility, myself and four of my closest friends made a pact that whoever (if anyone) was to survive this nightmare they would fight for everyone to get to the bottom of what was unfolding, seeing it through to the end to get the answers and truth.. I can still see all of their sad worried faces now when I think about that moment (which I do every day) . I am the sole survivor of that particular group.
18. The school never really addressed the rumours surrounding AID's; it was just haemophiliacs getting ill.

19. We were all about to leave school and should have been looking forward to our lives, futures and getting out to the workplace. Instead we realised that it could all be ripped away from under us.
20. I was originally told that my Treloar's records had been destroyed. However, recently a nurse at Basingstoke (where the records were transferred to) then told me that some notes (including some of mine) had been located in a cupboard. These have now been provided to me.
21. My Treloar's records contain sheets where the site of the bleed, symptoms and treatment were recorded. This sheet also had a space for any reaction to treatment to be recorded. An example of this sheet is now shown to me marked **"WITN1432004"**.
22. There are antibody test records that date back to 1979 which show that I tested positive for hepatitis antibodies as early as January 1979. A copy of these results is shown to me marked **"WITN1432005"**. I also note that my pathology records were marked "Hepatitis Risk" prior to this. The first record marked "Hepatitis Risk" is dated 5 October 1977 and is shown to me marked **"WITN1432006"**.
23. There are also records which show that Liver Function Tests were being carried out as early as April 1977.
24. There is also a note in my records from the Autumn Term 1979 which states "SGOT (since Jan 79) slightly raised.." I understand that raised SGOT is an indication of damage to the liver. This is also referred to in a letter from Dr Aronstam dated 25 March 1980 now shown to me marked **"WITN1432007"**. It appears that my SGOT was measured from the date I started at the school in September 1976.
25. It is also clear that they were testing for inhibitors from 1976. A copy of these results is now shown to me marked **"WITN1432008"**.
26. When I was about 25, Hepatitis C was being mentioned. I didn't really listen to doctors too much as I felt reasonably ok – I just wanted to make the best of

my life (however long or short it would be) My thoughts were at the end of the day if I was infected I was infected – I couldn't change that.

27. In or about 1991 I went for my annual haemophilia review. It was here that I was told that I was infected with Hepatitis C. It was a very casual comment, and I was not provided with any real information about the disease. I was told that no one really knew much about it. The doctor was extremely guarded and simply told me to be careful. He did not provide me with any information or advice as to the possible routes of transmission, which I consider very reckless. I recall driving away from the meeting in shock, thinking that I needed to focus on my life ahead of me and that I would never go back there.

28. When it was finally spelt out to me what Hepatitis C really meant I had tunnel vision and tried to blank it out of my mind. I just thought "don't look back." I was 30 years old before I was given any advice about the routes of transmission for Hepatitis C by which time I felt it was all too little, too late.

29. It is clear from my medical records that it was known I had a liver issue in 1980 because I had raised Liver Function Test results. I remember being told to avoid alcohol when I was at Treloar's but I was certainly never advised that I had or was at risk of hepatitis. There is now shown to me marked "WITN1432009" a copy of the letter which states it was known I had Hepatitis C in 1980 (although I imagine it would have been referred to as 'non A non B' at that time).

Section 3. Other Infections

30. I believe I was exposed to Hepatitis B because I was told that I was immune to Hepatitis B through previous exposure.

31. I have received about 3 letters warning of my risk of vCJD as I was treated with a batch of blood product that tested positive for the disease.

32. Although I realise the seriousness of my infections I tried to live a full and normal life for as long as possible. Obviously I worry about my life expectancy and myself and my family's financial insecurity which is caused by them. Obtaining medical treatment on the NHS is hindered because of this. The most recent example is listed below.

33. It took over 2 years for me to obtain confirmation that I could have important ankle surgery because Royal Surrey Hospital refused to operate on someone who could potentially have VCJD. I made the point that if I had been in a car accident and arrived at A&E they would treat me. The Chief Executive accepted this was correct but said that as they now knew me they would try to send me to a London hospital instead if I was ever presented to A&E. After much deliberation and delay I eventually had the surgery at Basingstoke Hospital.

34. When I finally received the treatment and was in recovery immediately after the surgery, the doctors rushed in and asked to take blood tests from me as one of the operating doctors had received a needle stick injury. I refused as I had just woken up from surgery and told them they would have to wait until I was out of recovery. A week after being discharged from the hospital, they asked me to come back in for more blood tests. Obviously they take this very seriously.

Section 4. Consent

35. I or my parents were never informed that I was being tested for Hepatitis or HIV; nor did I consent to the same.

36. As stated above, my blood was regularly taken at Treloar's for testing. Neither I nor my parents were told what tests were being done or why. I am convinced that many of the pupils at Treloar's were monitored very carefully and that they did all the tests that they could, possibly for commercial interest and/or financial gain? Initially we did not know what products we were being given because they were all pre mixed. When this changed you could tell

which factor you were getting because the Oxford factor was in yellow bottles and the American factor was in blue bottles.

37. My parents were also not informed about any of the treatments I was receiving whilst at Treloar's and also never consented to me being tested.

38. I do not have anything against Treloar's as an establishment. I believe that they tried even though what they were doing was wrong both legally and morally. I believe that because of my age, my parents should have been given more information and choice regarding treatment regime.

39. My parents have confirmed that they never received anything from Treloar's regarding my medical treatment or Hepatitis infections

40. I have done my own research into this scandal over the years and am convinced this was not an accident this was negligence! The knowledge that blood products were contaminated was there and the whole problem and issue could and should have been handled very differently. When I was at Treloar's I was just one of a number of guinea pigs there who unknowingly were being constantly monitored and assessed regarding infections.

41. Once I left Treloar's I only went to medical appointments when necessary. I felt i was part of an experiment that had gone badly wrong killing most of my friends and making the ones that survived terminally ill. I just wanted to focus on making the most of whatever time I had left.

Section 5. Impact

42. It was an extremely difficult time being at Treloar's with the hysteria surrounding AID's whilst my friends and classmates were falling ill and dying around me. There isn't a day that goes past without me thinking of the pledge I made with my friends to keep fighting for the truth and justice.

43. Whilst I was reasonably physically okay in the few years after leaving the school, the emotional toll of attending the funerals of my school friends up to 10 times a year is indescribable. They were all in their 20s, young men with their whole lives ahead of them. There were people older and younger than me dying, I lost many close friends. By the time I had seen 20-30 of them die I became slightly hardened to it all, as it was the only way to cope so I distanced myself from my friends at the school, no longer attending reunions. Every day I thought "there for the grace of God go I." Obviously I consider myself extremely lucky to have survived this haemophilia holocaust.
44. Sometime after I left Treloar's I remember I saw Dr Wassef in the corridor at Treloar Haemophilia centre. He asked me to sign something – he said that there would be compensation due in the future and I should sign it so he could put me forward.
45. After I was told about my infections and, having spoken to others who were infected, I was worried about my life expectancy and future. I wouldn't be able to get life insurance or a mortgage. I therefore started looking for a job with tied accommodation. I started working for the Parks Department of the local council. I chose to tell nobody about my haemophilia in fear of reprisals and unnecessary discrimination.
46. After about 2 years, they one day saw the disabled badge on my car and found out that I was a haemophiliac. Staff were worried about the link between haemophiliacs and HIV/Hepatitis, The personnel dep't told me that if I left the job immediately, they would give me 6 months' pay and provide a council flat. I felt that I had no option other than to accept their offer. I did feel bullied, angry and somewhat ashamed.
47. My first wife and I moved into the council flat that was offered to us in a big housing block, but it was far from ideal. I was determined to pick up the pieces and try again. I became a service engineer for Currys. We managed to get a mortgage approved without me declaring my haemophilia and with little

medical history asked for. We moved into a rundown, 3-bedroom house that needed a lot of work.

48. During my 10 years working for Currys my health deteriorated and I increasingly felt the symptoms of Hepatitis C. I was constantly fatigued and very lethargic and was also becoming muddled and more forgetful. I therefore decided to leave Currys to start my own business servicing white goods in the 1990s. This allowed me more flexibility enabling me to take breaks when I needed and meant I wouldn't have to worry about trying to work when I was ill but of course I wasn't earning. I could now manage my work pattern.
49. The business did very well and I was creating around £50,000 profit each year, despite my fatigue and poor health. During this time I would wake up, do jobs in the morning and make sure I was home by midday to sleep. By around 1pm each day my body was physically exhausted and would be screaming at me to fall asleep, meaning I would sleep 1pm-5pm and then manage to stay awake until 10pm before falling back to sleep.
50. I do wonder what may have become of my business if I wasn't suffering with Hepatitis C, as I would have been able to work full days, employ staff and grow the business. However due to my disease I could not take the risk or responsibility of employing and paying others, I just wanted to ensure that my family were provided for.
51. I had to give up my business when I went through treatment to clear the Hepatitis C virus as I was physically incapable of working by this time. My first marriage also broke down at this time, and although this is not entirely down to my infection and treatment it definitely contributed.
52. I have been diagnosed with cirrhosis of the liver which has, in turn, resulted in the onset of type 1 diabetes because my liver is so weak.
53. I feel like my children have missed out as a result of my infection. I didn't tell my boys about my illness/infections until my oldest son was 16, but it must

have been difficult for them growing up with a dad whose main focus was just making it through the day.

54. I have tried to shelter my parents from a lot of what I have been through, especially my mother as she feels guilty for being a carrier of haemophilia.

55. I am lucky to have been surrounded by such loving friends and family who have not only supported me emotionally, but also financially. Of course I am eternally grateful for this but feel without my infections it would have not been necessary. My career and earnings potential was on target for an above average person and I would have been able to provide financial security for myself and my family including pension arrangements. Sadly I cannot do this.

56. The stigma surrounding haemophiliacs following the infected blood scandal has been tough to deal with, from childhood to finally losing my job with Guildford Council. Even today I have NHS dentists refuse to operate on me, which is difficult as private dentists are so expensive.

57. I have only ever told the people who are closest to me about my disease, and even then I am not forthcoming with information about what I have been through. I also remained quiet about my illness because I didn't want my sons to be bullied at school. The only reason I have now decided to waive my right to anonymity is because they have grown up and I feel there is now more understanding of the medical issues involved..

58. I consider myself extremely fortunate that my current wife was willing to overlook my health problems and the stigma arising from my infection, and I now live happily with her and her two daughters.

Section 6. Treatment/Care/Support

59. I was continually told by doctors that there was no effective treatment for those with Genotype 1B and my distrust of doctors grew. I also saw what the

horrendous side effects that treatment had done to people I knew who were infected.

60. I was giving up hope of curing the virus when I privately funded a consultation with Professor Roger Williams, a liver specialist on Harley Street. I knew this man was independent and top of his game and would give me an honest opinion. This was in or about 2012. I had done my research and saw he had pioneered the first liver transplant and treated George Best. At that stage Interferon free treatments were only just being talked about.

61. I visited Prof Williams of my own accord and with no appointment. I took some of my notes and my most recent blood test results. He was horrified by my story and after reading my blood results, he was amazed I was still walking around. He told me these interferon free treatments that I was asking about will not be available to him or the NHS for three years. He then brutally said "looking at your history and blood test results you are unlikely to be alive in one year let alone three. You need treatment NOW!" He told me to leave it with him and he would try and sort something out for me. I felt that I had been dealt the final blow.

62. Within a week, and totally free of charge he had telephoned and in writing referred me to Graham Foster at the Royal London Hospital research unit. When I went to my appointment he discussed some clinical trials with me and it became acutely apparent that the trial centre was crying out for haemophiliacs like me to trial these new drugs but could not fill the spaces required. This I found totally appalling. The first was Gilead but I was refused this because of my liver condition and diabetes. I was therefore put onto the second option of the trial offered by the German company Boehringer Ingelheim. This was a 6 month trial run by the NHS but funded by the drugs company. There were side effects from the treatment which resulted in my skin severely blistering and itching, and extreme photosensitivity; I was unable to leave the house without factor 50 sun cream on. Although the treatment was terrible I was determined to finish the course because I knew it was saving my life.

63. Following the treatment I successfully cleared the virus. I have been clear for 5 years now and feel better than I have in 20 years. I can now go a day without needing to sleep although I still often feel fatigued and mentally vague and damaged. My liver remains cirrhotic and I struggle with daily life.
64. Before starting the treatment to clear the virus I had gone to my GP suffering with depression, who recommended I see a counsellor. I visited the counsellor 3 times and I found it quite helpful to have someone listen to my story and what I have been through in a safe and confidential environment. She said she had never heard a story like mine before, and found it quite disturbing. The only thing she could compare it to was a soldier whose squad had been killed at war. She told me my feelings were equivalent to survivor guilt.
65. My first marriage was struggling already at the time of my treatment and it broke down shortly afterwards because my health was so bad. We were under huge financial strain because I couldn't work. The boys were teenagers and needed money so the timing of my treatment wasn't great.
66. My family were very supportive both emotionally and financially.
67. Three years ago I was lucky enough to meet my current wife who has 2 children from a previous relationship. I felt I had to tell her straight away about what had happened because I had strong feelings for her. It was a big ask for her to take me on given my health problems. She has and continues to be a massive support to me.

Section 7. Financial Assistance

68. I have received the Stage 1 and Stage 2 lump sum payments from Skipton. My application to the Skipton Fund arose as a result of me seeing Dr Williams
69. I have no income now and am reliant on benefits.

70. I currently receive the enhanced rate of PIP and receive monthly payments from the EIBISS.

71. I have not had any problems getting payments from the Skipton Fund however I do think the payments we receive are unfair. I was a hard worker on good money with much potential. Now I don't even receive an average salary and have no pension funds or life insurance and am unable to provide any financial security to my family.

8. Other Issues

72. My medical records are incomplete. My Treloar's records do not contain any information about HIV or the testing that was carried out for this. All references in the medical chronology to the same have come from my other medical records.

73. I do feel cheated, wronged and bitter about what has happened to myself and other haemophiliacs. I believe this whole scandal was totally avoidable and the cover up that has followed is a national disgrace. Although I am not on a witch hunt I want an acknowledgment of what has happened for me and my family along with recognition to all those who sadly lost and continue to lose their battle.

Anonymity, redaction and disclosure

74. I do not wish to be anonymous.

75. I wouldn't choose to give oral evidence but if the Inquiry felt it was necessary to hear from me or to clarify anything in my statement; I would answer whatever was needed.

Statement of Truth

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

Signed

GRO-C

S. S. Al-Hadi

Dated

28th Nov 2016

MEDICAL SUMMARY

MEDICAL SUMMARY

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

- 18.08.1976 Letter from JM Matthews (Oxford Haemophilia Centre) to St Mary's Hospital, Portsmouth. This pleasant young boy with factor IX deficiency (0-1%) who was on holiday in the area, attended this Centre on 12th August 1976 complaining of low abdominal pain.....He was given a dose of factor IX concentrate and allowed to continue his holiday.
- 21.09.1979 Letter from St Mary's Hospital, Portsmouth to Dr McHardy, Florence Treloar School. This child was diagnosed...in April 1968 as having Christmas Disease and from June 1970 he has been under my care....Treatment consisted of units of Plasma backed up with Factor IX.
- 15.10.1979 Lord Mayor Treloar's records. Autumn Term '79. Bio: SGOT (since Jan 79) slightly raised....
- 16.10.1979 Hospital records. Christmas disease. To Mr Ogos for extractions.
- 16.10.1979 Letter from Consultant Orthodontist to Mr Ogos (Consultant Oral Surgeon). I wonder if you would see this young man who was referred to me recently in Alton. He has a very severe Class III malocclusion which reflects the underlying skeletal pattern which is beyond the realms of orthodontic treatment. He is at present too young to consider surgery, but I thought it would be a good idea to relieve the crowding in the upper arch by removing 5/4....PS. I think Mrs Nicholls would probably like to be present at your consultation with Steven.
- 12.12.1979 Letter from M Wassef to Prof Lee. Biochemically his SGOT has been on the whole slightly raised since January 1979.
- 25.03.1980 Letter from A Aronstam to Professor Lee (St Mary's Hospital, Portsmouth). His SGOT has been persistently, although not greatly raised since January 1979.

- 11.11.1985 Letter from A Aronstam (Consultant Haematologist) to GP. There is no stigmata of AIDS and his last test for antibody HTLV III was negative.
- 20.01.1989 Anti HIV negative.
- 04.12.1989 Letter from M Wassef to GP. His HIV antibody was negative 03.10.89.
- 23.11.1990 Letter from M Wassef to GP. Seen for general review. He bleeds once every two months mainly into his muscles and most of his bleeds are traumatic in nature. He is now doing very well indeed on twice weekly prophylaxis with Factor IX and has had no complaints regarding his right knee or left ankle.....We have taken a blood sample today to repeat his HIV antibody test. His previous test was negative on 3 October 1989.
- 24.11.1990 Anti HIV negative.
- 28.11.1991 Anti HIV negative.
- 10.12.1991 Letter from M Wassef to GP. Attended the Haemophilia Centre on 28 November 1991 for general review.....A blood sample was taken to repeat his HIV antibody test. He was anti HIV negative on 23 November 1990. This sample showed antibodies to Hepatitis C virus. I have explained to him that the implications of this are at present unclear and that it is by no means certain that the presence of the antibody to this virus implies immunity nor does it guarantee the absence of future chronic liver disease. The liver function tests for the past four years have been normal apart from the mildly raised Gamma GT.
- 12.05.1992 Anti HIV negative.
- 21.01.1993 Anti HIV negative.

- 04.02.1993 Letter from M Wassef to GP. Attended the Centre on 22 May 1992 and 21 January 1993 for general review.Because of reports of Hepatitis A infection in haemophiliacs receiving Factor VIII concentrate we have been advised to test all our patients for anti HAV with a view to immunising those found negative. A blood test on 21 January 1993 showed no antibody to HAV and I would be most grateful if you would arrange for his vaccination with Havrix. I have already explained the value of immunisation to him and he is agreeable to this.
- 28.01.1994 Anti HIV negative.
- 31.01.1994 Letter from M Wassef to GP. Attended haemophilia centre on 1 July 1983 and 28 January 1994 for general review.....He has not been to see you regarding his Havrix immunization since I last wrote to you in February 1993 and I have urged him to do so. With regard to Hepatitis A virus, I have explained that sexual transmission is recognised and although the risk appears to be low at 3%, it is advisable to discuss the current data on sexual transmission with his partner for a joint discussion to be taken in respect of barrier contraception.
- 28.07.1994 Anti HIV negative.
- 13.02.1995 Anti HIV negative.
- 21.11.1995 Anti HIV negative.
- 08.05.1996 Letter from North Hampshire Haemophilia Centre to Southampton General Hospital.....send this patient an appointment direct in due course to see you regarding his HCV infection. He suffers from severe Haemophilia B and has antibody to HCV and is PCR positive. His AST results were occasionally mildly to moderately raised between September 1980 and November 1982, but within normal range thereafter. He has no signs or symptoms of chronic liver disease. He

is immune to HBV through previous exposure and is immunised against HAV. He is HIV antibody negative.

- 10.10.1996 Letter from M Wassef to GP. Seen in Haemophilia Centre on 4 April and 4 October 1996 for general review.....he exhibited none of the stigmata of chronic liver disease....His FBCs and LFTs' results were within normal range and he was HIV antibody negative when last tested on 4 October.
- 03.06.1997 Letter from North Hampshire Haemophilia Centre to Dr Ramage (Gastroenterologist). He suffers from severe Haemophilia B and had antibody to HCV when first tested in November 1990 and is PCR positive.....He was initially referred to Professor Arthur at Southampton in May 1996 but did not keep his appointment. When he attended the Haemophilia Centre on 27 May 1997 I explained to him that we now refer all our patients with HCV infection to you at North Hampshire Hospital and he was quite happy to be seen there. He works as a Service Engineer and will only attend our clinics during his holidays as he does not wish to miss a day's work....
- 03.06.1997 Letter from M Wassef to GP. With regards to his Hepatitis C infection, he cancelled his appointment with Professor Mick Arthur in the Liver Unit at Southampton Hospital. As we now refer all our new patients with Hepatitis C infection to Dr Ramage, Consultant Gastroenterologist at North Hampshire Hospital, he was quite happy to be referred there....His FBC and LFT results on the day were within normal range and he remains HIV antibody negative.
- 24.06.1997 Clinic notes. Alt day factor IX. HCV infection – known 1990. HCV positive. LFT abnormal 1980 but now normal. HBV HIV negative.
- 25.06.1997 Letter from Dr Ramage to Dr Wassef at Treloars. I note he has severe haemophilia B and is having factor IX concentrate alternative days currently. He seems to have a bleeding episode about once a month,

but is managing to lead a normal life otherwise. I note he works as a service engineer in Godalming. I note he was known to have hepatitis C infection in 1980 and is known to be PCR positive. I see that his AST results were abnormal in 1980 but are currently completely normal and he feels well. He has never been jaundiced and has had no dark urine....On examination he looked well, there were no signs of chronic liver disease. ...I have given him some information about hepatitis C. We discussed treatment with Interferon and agreed that, in view of his normal liver function tests, Interferon treatment was probably not going to be beneficial. He is generally in agreement with this and is going to think about it but I think it may be unreasonable to expect him to use Interferon for six months if his LFTs are completely normal.

13.08.1997 Ultrasound of liver normal.

01.12.1998 Letter from Dr Nokes to GP. Haemophilia Review Clinic. In the meantime we will book him in to the joint orthopaedic/haemophilia clinic and check his bloods for HIV and Hepatitis C RNA.

Feb 2009 vCJD letter from Basingstoke and North Hampshire NHS Trust

02.03.1999 Referral from Consultant Rheumatologist to Chiropody Department enclosing a summary.

Diagnosis: severe Christmas disease

Chronic Hepatitis C Infection (**but HCV RNA negative**) – this was typed but then crossed out.

Current status: Haemophilia well controlled on alternate day prophylaxis with Replenine as and when required.

Joints: End stage haemophiliac arthropathy of L ankle with equinus and valgus deformity.

HIV Status: Negative

Liver: Hepatitis A; immune through previous vaccination (Aug 94)

Hepatitis B: immune through previous vaccination

Hepatitis C: Anti HCV antibody positive.
HCV/RNA +ve.

15.10.1999 Letter from Dr Nokes to GP following Haemophilia Review Clinic. There has been considerable deterioration in his left ankle.....It is mainly problematic when he gets home from work and has a lot of difficulty getting off to sleep. At that time he describes the pain as particularly severe. There have been no further bleeds and he is not taking prophylaxis at the moment.....His last appointment with Dr Ramage for hepatitis C was some two years ago. Liver function is reasonable...He drinks approximately 20 units of alcohol per week and I will attempt to expedite an appointment with Dr Ramage and myself at the joint clinic some time in the near future.

08.06.2000 Arthrodesis of left ankle.

20.10.2000 Regular Clinic Review. On examination he looked well, there were no signs of chronic liver disease....Liver function tests are almost normal with just an elevation in the GGT to 108 (normal range 0-30). His full blood count is normal and we have also taken bloods for his yearly HIV and HBsAg check together with Factor IX inhibitor....Finally I have counselled him with regards to the small risk of passing on HCV to his wife. He tells me that his wife is aware of the risk but they do not use condoms. I have of course warned him against this and advised that he should be using condoms in future to reduce his wife's risk of HCV cross infection.

14.03.2005 Clinic notes. Chronic HBV/HCV infection – no problems. Last USS and LFT in 2004. HIV negative.