Witness Name: Robert John Nicholls
Statement No.: WITN6477001
Exhibits: **WITN6477001 - 2**
Dated: 31 August 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ROBERT JOHN NICHOLLS MBE, BEM

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 August 2021.

I, Robert John Nicholls, will say as follows: -

Section 1. Introduction

1. My name is Robert Nicholls. My date of birth is GRO-C 1940 and my address GRO-C. I am retired having served in the Navy for 32 years after which I became a Property Manager of the River Wey for the National Trust. I live with my wife, Diane, and we have two children together, Stephen and Penny.

2. I intend to briefly speak about my son Stephen's infection with Hepatitis C ("HCV"). In particular, the nature of his illness, how the illness affected him, the treatment Stephen received and the impact it had on him and our lives together. Stephen was born GRO-C 1967. He has provided a statement to the Inquiry (WITN1432) and gave oral evidence at the live hearings. As such, I do not intend to repeat what he has said.

3. I was not going to become involved and had decided to leave things to Stephen. However, having heard the evidence at Treloars related

hearings, I feel that I must offer some evidence from a parent's perspective (on behalf of Diane as well). Chiefly, we were never consulted or asked for consent regarding any medical trials and or tests while Stephen was a minor at Treloars. Also, that I did express my concern of the possible risk of American blood products to Treloars staff as early as 1979. Namely Dr Wassef.

Section 2. How Affected

4. Stephen was born on GRO-C 1967. On New Year's Day 1968, when Stephen was around 9 months old, he woke up crying with a swollen and bruised arm. We took Stephen to the Royal Hospital in Portsmouth. After a long wait and consultation questioning, they thought it was due to junior Asprin being given for teething and kept him in for observation and bed rest for a few days. This was most distressing for parents of a child of 9 months, as often the line of questioning inferred suspected baby battering.

5. As Stephen bruised very easily as a baby despite no longer giving him Asprin, we went to our GP to query this. We were then referred to a specialist at St Mary's Portsmouth, where Stephen was diagnosed with Christmas Disease, now known as Haemophilia B. He was by then, 1 year old. We were told that it was not as bad as 'regular' haemophilia, but of course it was - Stephen had less than 1% clotting factor.

6. When Stephen was losing his baby teeth, we would wake up to find blood everywhere, all over his bedding, pyjamas, face - it was like the scene of a hatchet attack. Stephen would have been around 4 years old then.

7. Dr O'Brien, at St Mary's Hospital Portsmouth, recommended that we used vipers venom to help with teeth bleeding issues. This would work for a while, however when Stephen went to bed and started sucking, the clot would come off and the bleeding would start again.

8. As other internal bleeds usually to arms and legs occurred, Stephen was subsequently treated with fresh frozen plasma FFP cryoprecipitate, and we would have to take him in at least every fortnight on average. At the time, due to its availability and expense, only Dr O'Brien could release the FFP cryoprecipitate for Stephen to be treated with it. Stephen would then be connected to a drip for hours, often overnight.

9. In 1971, when Stephen was 4, he ran up the garden to see me, but fell sustaining a deep cut above his eye, which would just not stop bleeding. So, we took him to St Mary's where he was admitted. We saw Dr O'Brien and after two days bleeding he eventually gave Stephen freeze dried Factor IX concentrate.

10. This is the first time we ever knew Stephen to have an injection to solve the issue, as opposed to being hooked up to a drip. After that, Stephen would always have an injection of Factor IX.

11. No risks regarding the concentrate were ever explained to us, only the benefits. The factor concentrate was beneficial, and in many ways, it was life changing for Stephen. Stephen would no longer have to spend hours, often overnight in hospitals, missing out on his schooling or time with friends and his family.

12. Being in the Royal Navy, I could be away for months at a time – the longest was ten months. I even missed the birth of my daughter. This made it difficult with Diane having to deal with Stephen's haemophilia alone, with our nearest relations in Kent and then no fast or easy communication with me overseas and mid-ocean most of the time.

13. We found out about the Lord Mayor Treloars College (LMTC), which is less than a 2hr drive away from where we were living, through an old Navy friend of mine Nick Young. He at the time had just left and was briefly on a teacher training placement at Treloars, as part of his resettlement, upon leaving, or just prior to leaving the Navy. With me so

often being away and for long periods, it made a lot of sense for Stephen to go to Treloars as a weekly boarder, rather than have the ongoing struggle at our local school.

14. In August 1976 after much deep thought, we resignedly submitted an application for Stephen to go to Treloars, for his education and wellbeing. We initially sought funding from the Hampshire Council who firstly said that it would not be in their budget to do so. Then I got medical support for an application to a Navy Special Boarding Education Scheme and finding the shortfall ourselves to fund Stephen's costs. However, eventually Hampshire Council agreed to fully fund a place.

15. Stephen's first term was in September 1976 at Florence Treloars school, and there was a group of around 8/9 haemophiliac boys there. My understanding was that this was the early stages of it being a centre for Haemophilia. It had previously been used for victims of Polio, brittle bones and to a degree those that had suffered as a result of the Thalidomide treatment.

16. Overall, Treloars was advantageous for Stephen. He went from not getting much education and having to keep out the way, to becoming one of the 'doers'. Stephen was not singled out, and was better physically able than most students there. In the early years, the haemophilia centre at Lord Mayor Treloar Alton Hospital was close to hand to the Treloars school, which meant that Stephen's bleeds had less of an impact on his education and his joints. Later, the school had the Medical Centre on site, which was an even better and an ideal situation.

17. Stephen would come home at weekends and school holidays. He would bring a supply of Factor IX with him.

18. In March 1979, Stephen started on the prophylaxis programme of treating his haemophilia. One day Stephen came home with extra factor, and explained to my wife who was already doing his home treatment, that he was now required to routinely have 2-3 injections a week to prevent any

accidents or his joints from getting damaged. I believe this was organised by Dr Wassef who was always mentioned by the boys and seemed very attentive and popular. Nor I, or my wife, were consulted or briefed as to what Stephen's new treatment regime would be. In fact, we were rarely if ever consulted about Stephen's treatment. However, the medical centres there were a vast improvement over Portsmouth but both were very re active, rather than pro active when it came to communication with us their patient's parents. We never signed any instruction that gave the college medical centres complete autonomy over Stephen's treatment but were grateful for the medical care of our child who was "out of parental sight so to speak".

19. In September 1976, at his start at the lower Florence Treloar School we signed a loco parentis form in case Stephen had an accident and needed treatment immediately. It was like the sort of consent that one would sign if your child was going off to Scout camp. (Exhibited as **WITN6477002).**

20. We did not give permission for all of Stephen's haemophilia related treatment to be done without our consent. Neither were we consenting to non-emergency treatment, whereby our consent could have been sought within a reasonable time frame. The form explicitly states that every reasonable endeavour would be made to gain our consent, prior to treatment. I cannot remember one incident where we were called in to consent to treatment. I particularly remember an example of receiving a letter saying Stephen had had two teeth removed; Neither Diane or I can remember ever being told at the time as we naturally would have been concerned of how the bleeding was to be managed.

21. The Factor IX at this time came from Oxford, and had Churchill Hospital printed on the bottle label. I understand that is where it was made. Stephen had no trouble with the prophylaxis treatment.

22. When Stephen was 12, in 1979, he came home all excited saying that he had new stuff from America, and that everyone was having it. I remember reading the package and there were no warnings. However, I had grave concerns.

23. After Stephen had been diagnosed with Haemophilia B and because I felt that I should do my bit in maintaining blood supplies, I became a blood donor. It was relatively easy to give blood whilst in the Navy, even when overseas, as blood bank vans would come to the ship when alongside (docked). The ship provided a ready supply of fit regularly checked men with good blood.

24. On one occasion whilst docked in America, I believe Baltimore but cannot be sure. I missed the donor van one day, but was told that I could go to the local donation centre instead. I got the location and duly made my way. The centre was in an extremely run down part of town. There was a queue of a dozen or so down the street and the condition of the people waiting to give blood, alarmed me. They were frankly druggies and drunks and not fit to give healthy blood - the individuals looked drawn and weak. I turned around and I didn't bother to enter the centre because of this.

25. When on RN shore patrol duties with local police I had seen Skid Row in New York and Baltimore, with all the druggies and down and outs lying in the street with their needles and syringes. This was long before the sterile one-off disposable syringe use of today. At that time things were un-sterilised with interchangeable syringes and shared needle use, so I had that in mind. This was the background I had to American blood when Stephen came home that day. Being a regular donor, I knew the USA blood could be a contamination risk of some sort from the standard of the 'skid row' donors I had seen in the past and wondered if this risk was really necessary for my son?

26. At the time I was unsure who to contact about this as the names I recall were a Dr Rainsford, Aronstram and Wassef. Dr Wassef was the name that was most familiar and that Stephen regularly used when talking about the medical centre at Treloars. I managed to ring him and told him that I was not happy with Stephen being given an American blood product and asking why he couldn't stay on the Oxford produced Factor IX? Dr Wassef sought to reassure me, saying that all the boys were on it now

and that there was nothing to worry about. However, he relented to my request saying that because Stephen was on Factor IX (as opposed to VIII) that it was no problem at all as there was no shortage of the Factor IX concentrate from Oxford. I recall the 10 min or so conversation well, as Stephen was so upset and very angry because he felt that he would be singled out as being the only one not on the American product. Also, my wife and daughter recall this 'family incident'. Fortunately due to that phone call, I managed to keep Stephen on the Oxford product.

27. As far as I am aware, Stephen stayed on Oxford Factor IX after this. He had a regular supply of Oxford Factor IX concentrate from Treloars until he left in June 1983. In retrospect, I believe that this greatly reduced the risk of Stephen being infected with HIV and dying of AIDS like so many of his school friends at Treloars. I am now of course aware that HIV contamination was present in some UK blood products at the time including Factor IX. Although the US blood product production used much bigger pools than the UK which would have made a risk difference, meaning that smaller batches could be recalled after any reported infection.

28. In retrospect I would very much like to know why at this time was commercial American Factor IX available and in use at Treloars when there was, as Dr Wassef had said, a plentiful UK supply from Oxford?

29. Apart from weekends and holidays, Stephen was treated at Treloars from 1977 until 1983 as a boarder. Being a book keeper my wife kept meticulous treatment records when Stephen was at home with us and sent them back with him so that they could audit and account for stock. Diane carbon copied all of her written records. There were copies of these in my son's medical records such as they are, when he eventually managed to get them at the start of the Inquiry. However very conveniently it seems, all of Diane's written records before June 1983 are missing. I have no explanation for this.

30. Stephen continued to get his Factor IX supplies from Treloars after he left the college from June 1983 up until 1991 and Diane continued to make written records until 1989 when Stephen started keeping his own records. Treloars were eventually able to provide copies of the records of Stephen's treatment from after he had left the college and continued to be treated there but none of the ones that pertained to when he was a boy boarding there. I have no explanation for this.

31. Treloars was a wonderful school, and benefitted Stephen in so many ways. Stephen enjoyed all the education and many out of the school activities it had to offer. He was even taken to New Foundland, Canada on a school trip. Also the medical side was much better than our local hospital`s centre in Portsmouth. Treloars medical centre did its best in the care of my son. However with hind sight, I think there are some things it shouldn't have done, and parental permission was not sought for some of the treatments and trials/tests undertaken.

32. I believe from Stephen, that each time they gave Stephen factor concentrate they would regularly take samples for tests and analysis. I now question what all these regular tests were for as we were never consulted about it. At the time, I thought it was for tests for Stephen's benefit but looking back at the now known long contaminated blood history of events, I believe at this critical period, this chance concentration of resident Haemophiliac Treloar boys under one centre was an irresistible, probably well-intentioned opportunity, for research, trials and analysis. I know that Stephen now firmly believes this.

33. In December 1991 aged 24, Stephen was made aware that he had been infected with HCV. By this time Stephen kept himself to himself with regards to his medical and health issues. He was very vague to us about his diagnosis. Stephen deliberately filtered the news as he knew we would worry. Later on, Stephen was informed that he had also been exposed to vCJD.

Section 3. Other Infections

34. Thankfully, Stephen was not infected with any other infection apart from HCV. Hopefully, the potential vCJD exposure will not come to anything.

Section 4. Consent

35. Whilst at Treloars, I believe Stephen was treated and tested, without our parental consent, notably I believe, for the purpose of well intended medical research, though we should have been consulted and given the opportunity to provide informed consent.

Section 5. Impact

36. The experience of administering Factor IX to Stephen has impacted my wife and I greatly. We feel a sense of guilt that we had probably helped make matters worse. This is on top of the guilt my wife has always felt for being a carrier of haemophilia B and passing it on to Stephen. It does not make any difference that she is not at fault. Diane still feels the guilt acutely.

37. **GRO-C**

38. We have always had a good close relationship with Stephen. We have never had any serious difficulties. We know Stephen has filtered and still does, what he wishes to tell us, trying to reduce our ongoing parental worries and concern for him.

39. Despite Stephen contracting HCV at Treloars, the advantages of sending Stephen there outweighed the disadvantages. Treloars was generally good, and they were all initially doing what they thought was best for the boys until medically and scientifically they got distracted, as I have described above.

40. We were shocked to learn that Treloars, without consulting us or obtaining our consent, had been doing some kind of trials on the underage haemophiliac boys against all kinds of ethics. It makes the 1945 Nuremberg medical trial protocols come to mind. However it is conflicting for us, we were and still are, so appreciative of all that the school gave to Stephen at that time, with the then general public deference to doctors and their "don't worry we know best" front, as it was back then.

41. Had Stephen never been sent to Treloars, I think the likelihood of Stephen escaping treatment with infected blood products to be extremely remote. I am convinced that had Stephen gone elsewhere, something else would have happened, either earlier or later, and Stephen would have been more isolated and may not have had the happiness and companionship that he had at Treloars.

42. As he was at school with a group of 80-90 haemophiliacs, they all had a sense of "we're in this together".

43. Of course, this has a massive downside. Stephen is very close with his old school friends, and used to go to numerous Treloars reunions, however these then turned into funerals. This greatly affected Stephen, and I remember him once saying in his mid 20s GRO-C GRO-C.

44. Jeremy Hunt the former Secretary of State for Health is our local MP. I have attended his local surgeries and even lobbied him in the house on two occasions over a three year period, certainly during the last ten years and while he was in charge of Health. I am afraid I cannot remember the specific dates or years. I once challenged him about the infected blood scandal and need for compensation. I remember Jeremy Hunt replying "Bob how much do you want?". I explained that it should all be done by effect and needs to a recognised scale, to

which Jeremy Hunt replied that if the government pays out it would have to come from the National Health fund, and that would mean less money to go to the hospitals. It felt like emotional blackmail to stop us from pushing further.

45. After I retired from the Navy in 1986, haemophilia had become associated with AIDS and it was in the press and all over the TV. We could see the negative reaction that people had to that, and so we decided not to tell any new friends or acquaintances that Stephen had haemophilia and risk further difficulties due to public ignorance and misinformation.

46. Around this time I recall, I even had to correct my own mother, who misguidedly was blaming the AIDS crisis on homosexuals. I had to explain it was much wider than that, and that HIV was being contracted through infected blood and bodily fluids putting anyone at risk and that it was a public health issue.

Section 6. Treatment/Care/Support

47. Stephen kept a lot of his treatment from my wife and I. Stephen was very hesitant about being put on Interferon, as it was only 60% effective and he had seen a lot of his friends become even more ill that they were from HCV symptoms and it didn't work in clearing it for many of them. I said to Stephen that I would pay for him to get a good Harley Street liver specialist advice. Stephen did the research, and said that he had found a specialist, and although he was expensive, he was the best. He was the specialist that treated George Best.

48. The specialist, whose name I cannot recall, was shocked at the state of Stephen's liver, and told him that he was in a terrible state with severe cirrhosis. The specialist mentioned the name of a drug that wouldn't be available in the UK privately for a year or so and NHS for at least two years and that Stephen hadn't got that long! Luckily the

specialist knew someone conducting some UK drug trials, and was able to link Stephen up with them.

49. Between 2009-2012, I can't be more specific (see Stephen's statement), Stephen did a drug trial and cleared the HCV virus. However, the damage to his liver had already been done.

50. Amongst other side effects, Stephen experienced photosensitivity and severe peeling to his skin during this treatment. During this time, I would go with him up to London for appointments and after some 6 months of the treatment, Stephen was finally given the all clear.

Section 7. Financial Assistance

51. During 2008/9 when Stephen was struggling with the effects of his failing liver and HCV, which was drastically reducing his income, I paid off his mortgage with my recent inheritance after the loss of my parents. This gave him some relief from the position he was in as a parent with two dependent young children and a home to run. Later, Stephen received money from the Skipton Fund, and now EIBSS. I understand that Stephen receives everything he is entitled to have.

Statement of Truth

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

Signed **GRO-C**

Dated 31-8-21.