

ANONYMOUS

Witness Name :

GRO-B

Statement No.

WITN37330010

Exhibits : WITN3733011 – WITN3733021

Dated :

16 August 2023

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF

GRO-B

I provide this second witness statement in addition to my first statement.

I, **GRO-B**, will say as follows:-

1. On 24th January 2020, I met with an investigator from the Infected Blood Inquiry, **GRO-D**, so that I could make a statement concentrating primarily on my late younger brother, **GRO-B: B** and my son, **GRO-B: S** and how they had been impacted – both of them severe haemophilia A sufferers. At the time, I did not have my brother's hospital records, but I did have his GP records and a copy of his UKHCDO record. Therefore I was not able to provide a complete account of what had occurred in my brother's case, but I was told that I could add the details at a later date.

ANONYMOUS

2. In addition, I had written to our local coroner and asked that the circumstances of my brother's death be reviewed. As this was the case, Mr. **GRO-D** told me that that part of story could be left until the coroner's investigation had been completed. Well over a year had passed when I received a copy of my first statement in May 2021. By then I had received my brother's hospital records and I set about adding facts to my statement from the information I had received as well as correcting the inaccuracies. Soon after this, I received word from the coroner's office that they would not be looking any further into **B**'s death.
3. With no help coming from the coroner's office, I felt I had no option but to continue with my own research and on Sunday 6th June 2021 I telephoned Mr. **GRO-D**. I spoke of information I had found regarding the heart-failure drug which had been prescribed for my late brother, **B**, and how I believed that this drug had contributed to his death. He responded with an email which said that a second statement would be drafted for me and that I would receive it by the end of the week. Unfortunately I never heard from him again and I did not receive the second draft statement. I expect that this is because there is a lot of work to be done for this Inquiry and I am not the only participant he is having to deal with. It has taken days for me to write just one statement, so I can't even imagine the amount of work he is having to do.
4. I know it may not mean anything to the reader(s) of this document, but on the day of my brother's funeral I made a promise to him that I would do all I could to make sure the truth about his ordeal is brought to light. **B** had deliberately left specific documents for us to view as he was sure that he would soon pass away. As his sister, I know that he did this because he wanted the truth to be told on his behalf.
5. I am aware that the drug I mention in the next few paragraphs, Entresto, was not designed specifically to treat any of the actual infections contracted through the use of contaminated blood products, but it was designed to treat the heart condition which I believe was related in some way to the infections **B** contracted and the treatment used for his chronic hepatitis C. This is the last thing I can do for my little brother so I ask that the Inquiry will allow me to tell the rest of his story for him.

ANONYMOUS

6. I have continued with my own investigations on behalf of both my son and my late brother because neither of them are able to do this for themselves. I intend to do this without fear or favour and tell the truth, the whole truth and nothing but the truth.
7. Firstly, concentrating primarily on my late brother, within his hospital records I found a carbon copy of a short letter written to our mother by (then) Consultant Haematologist, Dr T E Blecher, dated 23rd December 1980. The letter states : *'We have just been notified that there might be something slightly wrong with the batch of Factor VIII from which you were given six bottles for [B] [redacted] on 8th December. If [redacted]s have already had some of this new batch of Factor VIII, you need not contact us and can continue using the batch. If however either one boy, or both boys have not yet received any of the new bottles, would you please bring all the remaining bottles back to the Haematology Department. We will then exchange these for bottles from a different batch.'* The letter does not mention what the problem might have been or which brand of factor VIII had been supplied, but from his UKHCDO record and my own recollection I believe it could have been 8Y. [B] was 8 years old at this point. I do not know if the batch of factor VIII in question had been used or not.
8. As I did for my son, I created databases of [B]'s blood, liver and virology results, just so that I could see many results in date order at a glance because they were not received in order and it would save time when looking for particular dates and what was happening at that time. I can see from his liver enzyme database that his test results were abnormal from the earliest entry dated 7th February 1981 when he was 8 years and 7 months old, right up until his hepatitis C was successfully treated in 2017. The last abnormal test result in succession is dated 26th July 2017, at age 45. All of his liver enzyme tests after this date are normal with the exception of one test on 11th October 2017 which I am not entirely sure about because there are two sets of results for that same day. All of the enzyme results are identical except for his bilirubin. One set of results records his bilirubin at 30 and the other is 13. Around this time he was also diagnosed with thyrotoxicosis.

ANONYMOUS

9. I have copies of [B]'s factor VIII records for 1983 and 1984. In 1983 he was being treated with NHS factor VIII for the whole year except for three treatments on 5th, 11th and 15th November when he received 250 iu Cutters factor VIII on each of these dates. At that time he was 11 years old. In 1984, again, he received NHS factor VIII all year except for 5 treatments from 23rd to 28th August with a total of 56 units of cryoprecipitate. It appears that [B] could have been infected with hepatitis C before he arrived at Lord Mayor Treloar College in September 1986.
10. Upon further inspection of his hospital records I discovered that [B] had also tested positive for Parvovirus B19 IgG in 1999. I can find no indication of when this infection occurred. This may or may not be of interest to the inquiry, but we now know that this particular virus was also found to be in the blood products used to treat haemophilia.
11. As I mentioned in paragraph 77 of my first statement, after my brother's funeral I was invited for an informal chat by the haemophilia nurse at our local hospital. The consultant, Dr Charlotte Grimley, told me that my brother was 'warned about his drinking' and implied that the cause of his heart problem was more than likely alcohol related. What I find extremely distressing is that Dr Grimley did not take into account that my late brother's liver enzyme tests had not been normal since he was 8 years old and he had been infected with hepatitis A, hepatitis B, and chronic hepatitis C through the use of contaminated blood products when he was a boy. The test for Parvovirus was in 1999, but we have no idea when that happened. To my knowledge, hepatitis C and Parvovirus B19 as well as initial treatment for hepatitis C are also associated with liver, kidney and heart problems, but it appeared that she was trying to convince me that my brother was responsible for his own death because he had consumed alcohol in the past.
12. Although he was not feeling well, [B] did not want to cancel his holiday to Florida in June 2019. He felt it was his last chance to visit this place he loved. Before he left, he took a file case to our mother's house and informed us that if anything happened to him whilst he was away that we would find everything we needed to know in this file case. He did not survive to bring himself home.

ANONYMOUS

13. When I returned to England from Florida after visiting my brother and witnessing his death, I went to have a look at this file. In it were all his important papers. He must have felt that he was dying to leave these with us. The only medical papers we found were three letters written by his cardiologist, Dr Timothy Robinson, regarding switching his ACE inhibitor drug, Ramipril to Entresto – a combination of Sacubitril and Valsartan. One letter was to his GP and another was to heart-failure nurse, Darren Warrior, asking him to oversee the drug change. A third document was an A&E Medical Discharge Summary dated 28th May 2019 – two months after he had started taking Entresto and one month before he collapsed. Also, B's GP records say that they were prescribing Entresto '*as per cardiologist's request*'.
14. I had written to our local Coroner and asked that they investigate my brother's death because I felt his death certificate was limited in its explanation of what happened. Dr Robinson sent a report to the Coroner stating that the switch from Ramipril to Entresto was made by my brother's GP and a different community heart-failure nurse who he named in the report. He made no mention of the fact that he had initiated and asked them to do this.
15. Dr Grimley also prepared a report to the coroner in which she rewrote points from previous medical notes, stating Dr Gill Swallow (Consultant Haematologist) '*emphasised the need for him to reduce his alcohol intake*', again '*pointing the finger*' at my brother. From the earliest liver enzyme test I could find dated 7th February 1981 (age 8 years 7 months) to 26th July 2017 (age 45 years), every one of these tests is abnormal. Every test after that is within normal range. If my brother was a heavy drinker at that point, these results would have continued to be abnormal. I agree that he may not have helped himself by consuming any alcohol at all, but my brother was never an alcoholic. Also, he became teetotal for four years before he passed away and remained so until the end. This is why I find their insinuations intolerable.

ANONYMOUS

16. I am aware that the publications I have mentioned in the following paragraph are articles reporting on the findings of studies and not actual studies themselves. I mention this because I sent a copy of Dr Robinson's report and a copy of the third article I mention in the next paragraph to Mr. **GRO-D** in June 2021. From his email to me it appears that for some reason he thought I believed these were actual studies. I do not know if the documents I sent to him have been passed on to you, but I will include them in my exhibits.

17. I found articles online about the drug, Entresto, the earliest one published on 29th July 2019, just **GRO-B** after my brother's death entitled '*Novartis heart drug fails trial, curbing growth prospects*'. A second article was published on 1st September 2019 entitled '*Novartis PARAGON-HF trial suggests Entresto benefit in HFrEF patients but narrowly misses primary endpoint*'. A third article published on 12th December 2019 entitled '*Entresto Holds Up In The Real World ... But Not For Everyone – Drug not better than ACE inhibitor, ARB for black patients?*' A fourth article published on 17th May 2021 entitled '*Novartis' Entresto takes it 2nd failure of the weekend at ACC, showing no benefit in most dire heart failure patients*'. I believe these titles are self explanatory. As these articles were published **GRO-B** after **B**'s death, I wondered if he was taking part in a trial for this drug. I have no evidence of this but the timing of their publication has made me think about it.

18. I had also found reviews online written by patients who had also taken Entresto. Only a few gave this drug 10 out of 10 so it did work for some people, but over 50% of the reviews were by patients who said they could not tolerate the side effects of this drug and stopped taking it and/or the family members of patients were describing how their loved one died whilst taking it. I found this odd because Entresto had been described as a drug designed to prolong life and extend time to hospitalisation for heart-related issues, yet the reviews described intolerable side-effects and death shortly after commencing the use of this drug.

ANONYMOUS

- 19.** In his report to our local coroner, Dr Robinson addressed me personally and said that Entresto showed superiority over ACE inhibitor drugs. With articles and reviews such as those mentioned in the previous two paragraphs, I can not help but fail to share Dr Robinson's point of view. I believe that Entresto played a role in my brother's death because he felt ill enough to take himself to hospital two months after commencing this medication, then a month later he collapsed. He clung to life for another 11 days, but we were told he would not survive and agreed that his life support should be removed. We were and still are heartbroken that we had to make that decision.
- 20.** Many of the victims of this scandal were infected as children and their infections became chronic. Also in many cases, the victims were not informed for years even though their consultants knew of their infections. Through no fault of their own, the damage had already been done. It is absolutely unfair to then place any blame at their door. After finding out something as terrible as this, it is not for anyone to judge how they go about the lives they have to live which have already been made more difficult. It also does nothing but add insult to injury for the families of those who have died as a result of their infections and/or their subsequent illnesses and treatments.
- 21.** I will now concentrate primarily on the impact on my son, [REDACTED] S. All three of my haemophiliac brothers were initially treated with cryoprecipitate as young children and began using factor VIII in early 1980s. My son was born in [REDACTED] GRO-B 1986. Even though factor VIII was available and my brothers had already been using it for about six years, my son was always treated with cryoprecipitate for any bleeding issues he'd had. I believe this was done because it was known by then that the factor VIII products may have been contaminated and, with regard to blood borne infections, cryo was considered to be a safer product.

ANONYMOUS

- 22.** Although cryoprecipitate was considered to be a safer treatment for haemophilia in relation to avoiding HIV and hepatitis C infections, upon reading the Expert Report on Fractionation distributed by the Infected Blood Inquiry in 2021, I can see that it very likely played a part in my son's abnormal immunological functioning. After reading about this on page 73 of this report, I decided to research this issue further and discovered that immunological abnormalities, such as inverted T4/T8 ratio, are a common problem with haemophiliacs who had been treated with blood products, particularly those who had been given a product as impure as cryoprecipitate or plasma derived factor VIII. With this problem, patients who had received blood products would struggle with immune function problems.
- 23.** Further research led me to find the NICE guidelines for MMR vaccination which states : *'Antibody response to measles component may be reduced after immunoglobulin administration or blood transfusion. Leave an interval at least three months'*. Also, the JCVI minutes dated 23rd October 1987, page 4, item 4 states : *'.....immunoglobulin should not be used with measles, mumps and rubella vaccine.'* The following minutes dated 22nd April 1988 repeats on page 3 item 4 that: *'The first proof of the Memorandum on Immunisation Against Infectious Disease suggested that in the section on measles mumps and rubella (MMR) vaccine it is stated that immunoglobulin should not be used since it might interfere with the development of immunity against mumps and rubella.'*, but I would refer to the most up to date information which is the current NICE guidelines at the beginning of this paragraph. Either way, the JCVI knew that there was a risk of vaccine failure for recipients who had recently received blood products, but I (and I suspect many other parents of haemophiliac children) remained uninformed of this risk.

ANONYMOUS

- 24.** As I knew nothing of this, on 3rd March 1988 I followed the advice of health professionals and allowed my son to be vaccinated with the MMR – the first of it's kind to be used in the United Kingdom which contained the Urabe strain of mumps. The result of this for my son was that two weeks later he began to fall ill with cold/flu-like symptoms, which I was told to expect, but he did not get better he got much worse. The following week he collapsed with his first ever left-sided focal seizure, cyanosis and eventually fell into a coma whilst he was in A&E at Queen's Medical Centre, Nottingham. I have detailed what happened to my son in my first statement. When he was admitted to hospital on this occasion he was given his first ever dose of factor VIII and tested for HIV and hepatitis B without my knowledge. He was 17 months old. I have no idea which brand of factor VIII he was given at that time because I was not allowed to see him for several hours whilst he was being treated.
- 25.** On this admission to hospital my son undeniably satisfied all four diagnostic criteria for systemic inflammatory response syndrome, also known as SIRS. A patient has to satisfy two of these criteria for a SIRS diagnosis: white blood cell count (WBC) above 12; temperature of above 38°C or below 36°C; more than 20 breaths per minute or PCO₂ below 32 mmHg; heart rate of more than 90 beats per minute.
- 26.** My son's results at that time showed white blood cell count (WBC) 23.5, temperature 39.8°C, breaths per minute could not be calculated because spontaneous breathing ceased after he was given rectal paraldehyde so PCO₂ was 3.88 KPa which, when converted to mmHg, is equivalent to 29.1 mmHg, heart rate of 110 beats per minute. Two or more of these four symptoms is an indication of dysregulated immune system functioning. As [S] had all four, he was then at risk of developing sepsis, which he did, as his immune system then switched to a pro-coagulant state by creating more platelets, which is evident in his blood results. According to the blood results sheet, normal platelet count is between 140 to 400. [S]'s platelet count had gone up to 680. At it's worst it was 929. My son's life was in danger.

ANONYMOUS

- 27.** This is the only logical explanation I can deduce for why my severe haemophiliac son, who at that point had not had any clotting treatment for a month, suddenly developed a blood clot on the right side of his brain when his factor VIII level at that time would have been <1%, possibly zero.
- 28.** The 'Urabe' MMR vaccine was discontinued in the UK in 1992 due to its reactogenicity and its tendency to cause neuro-inflammatory conditions, such as aseptic meningitis in young children, which had been previously underestimated. It was then replaced with a safer version with a different strain of mumps, the 'Jeryl Lynn' strain.
- 29.** After reading the Expert Report on Fractionation sent to me by this Inquiry, it makes sense to me that lack of protective antibody response was the reason my son did not develop immunity to the measles component of this product because he had been given cryoprecipitate just ten days before he received it when the guidance actually says that there should be an interval of at least 3 months after receiving blood products prior to MMR vaccination. Cryoprecipitate is a product which contains a number of blood components, including immunoglobulins, which can interfere with immune system functions. In fact, my son had received a total of 8 doses of cryo within the three months immediately prior to receiving this vaccine. This lack of immunity would have allowed the measles component to repeatedly attack his central nervous system during that year because his immune system could not neutralise it. His symptoms appeared to follow the path of un-neutralised measles virus infection; atypical APME, MIBE and SSPE, all at the specified intervals as his immune system went horribly awry. I also believe that lack of protective antibody response may also have been the reason that my brothers' hepatitis C infections became chronic as their immune systems were never able to neutralise this virus naturally.

ANONYMOUS

30. I have already made an official complaint to the Queens Medical Centre, Nottingham, about this – not only about the fact that they did not inform me about the cause of my son's condition and the state of his immune functioning at that time, but also the fact that they did not inform me about the HIV and hepatitis testing they took the opportunity to carry out on my (then) 17 month old son without my knowledge. They responded by claiming that I was informed and pointed out a note in his records which said 'as D/W parents'. I do recall that a doctor did speak to [S]'s father and me on the PICU, but only to tell us that they did not know what was wrong because the tests they had performed did not show anything so they wanted to perform a lumbar puncture. The doctor absolutely did not specify to us what tests had actually been carried out. I have already provided evidence to the Inquiry with my first statement, Exhibit WITN37330004, a ward nursing note which states '*Still awaiting results of HIV testing. parents not aware of testing*'.
31. It appears that they also did not even notice that my son's immune functioning had gone haywire (they certainly did not mention it, nor did they mention sepsis) and have tried to convince me that the vaccine he'd received could not have done this because, they said, that particular vaccine was not launched until October 1988. The launch date is correct, but I have also discovered this product was actually being trialled in the UK in 1987 and 1988. Nottingham and Oxford were conducting studies on it at that time, so it was actually in our city when my son received it seven months before the launch. I remain dissatisfied with the lack of transparency in response to my complaint and I have been invited to take this up with the NHS Ombudsman.
32. As haemophilia A is within our family, we were all invited to attend the Queens Medical Centre, including those of us unaffected by the gene, to be vaccinated against hepatitis B because of the risk of infection from contaminated blood products. We attended on 21st December 1988. [B] also attended because he was home with us from Treloars for the Christmas holiday.

ANONYMOUS

33. Shortly after my brother had arrived at Treloars, aged 14, in September 1986, he was tested for hepatitis B antibodies. His records show that result was 'equivocal', but three months later he had tested positive for hepatitis B core antibodies on 6th January 1987, which is a definite marker that he had been previously infected. An 'equivocal' result may indicate a recent infection, but he had obviously recovered so he must have been immune. Despite this he was vaccinated against hepatitis B with the rest of us when he did not need to be. The haematology consultants were already aware that my brother had been previously infected because his test results from Treloars were being sent to the Queen's Medical Centre in Nottingham for the attention of consultant haematologist Dr E A French and are present in his Nottingham hospital records. To our knowledge, [S] was never informed that he had been infected with hepatitis B.
34. We were all vaccinated on that day with Engerix B recombinant hepatitis B vaccine (produced by GlaxoSmithKline), including my son, [S], [GRO-B] his second birthday. He had the second of this course of three vaccines on 18th January 1989 and the third on 21st June 1989. Two weeks after the third dose he fell asleep, only waking when I roused him for feeding. He would feed reluctantly then go straight back to sleep. He had not injured himself in any way and he had not had any seizures. On 9th July 1989, which was day three of this somnolence, I took him to A&E at Queen's Medical Centre (QMC) because something clearly was not right.
35. I can see on his factor VIII record on that same day and the following day he was treated with clotting factor for an 'intracranial' issue. His hospital nursing notes also state that he was being treated for a 'suspected' intracranial bleed. The thing is, I was never told why he was being treated. All I recall is that he was in hospital for a few days then I was told that he seemed well enough to go home and he was discharged.

ANONYMOUS

36. I remember this incident, but I have only very recently discovered that when an infant / young child goes to sleep for two days, this is a neurological event which indicates that the child has brain inflammation/damage. This is not normal and it is not 'just one of those things' as I was led to believe, it is a nervous system disorder as stated in the Engerix B package insert under the heading '**6 Adverse Reactions**, subheading **6.1 Clinical Trials experience**, Incidence <1% of injections *Nervous System Disorders: Somnolence, tingling*'. I was never given any of this information at the time. I only found it in September 2022. If I had been given this information at the time I would have had some idea of what to look out for and would have known that my son needed medical attention a lot sooner. Instead, my child was in this state for 3 days because I had no idea that this vaccine could possibly do this to him or how serious this was because he had not had any seizures – he simply fell asleep. Even after I had got him to hospital, nobody said a word to me about this brain inflammation or what could have caused it. They simply treated him for it then sent him home.
37. I also very recently found the result of a test for group A haemolytic streptococci in a batch of papers given to me by the hospital separately from my son's hospital records. The sample for this test was taken on 9th July 1989, the same day my son was admitted to hospital after being asleep for 3 consecutive days. I do not recall ever being told about this test result, which says that this bacteria had been isolated.
38. I looked further into this and found a health page on the BBC's website published on 9th December 2022 at <https://www.bbc.co.uk/news/health-63836093>. I do not know how much was known about strep A at the time, but whatever was known, it was not shared with me. I had never heard of it in 1989. Under the heading 'Is Strep A dangerous?' it states : '*Very rarely, strep A can also cause something called invasive group A streptococcal infection or iGAS. This can be deadly. Invasive disease happens when the bacteria get past your body's immune defences. This can happen when you are already ill or are on treatments, such as some cancer therapies, that can affect your immune system*'.

ANONYMOUS

39. Further down the page, it then goes on to say that a parent should call 999 or visit the accident and emergency department if their child will not wake up or stay awake.
40. My son did not show any symptoms of viral or bacterial illness before he was vaccinated on this occasion. If he did, I would like to believe that the nurse would not have vaccinated him at that time. My son and I lived alone at that point. I was not ill. He did not attend playgroup or nursery because at 2 years old, he was too young. He did not start nursery until he was 4 years old because nobody would accept him until a social worker helped to find a placement. I also do not recall that any of the family members we visited were ill.
41. As I have previously stated, my son was given his third Engerix B vaccine on 21st June 1989. There were two neurotoxins in this product at that time, 12.5 mcg thimerosal (mercury-derived) preservative and 250 mcg of aluminium hydroxide adjuvant had been added specifically to affect the immune system because the inactivated 'piece of protein' in this product from the virus can not do this. As the BBC's website states, serious symptoms can happen *'when you are already ill or are on treatments, such as some cancer therapies, that can affect your immune system'*. My son was not already ill nor was he being treated for cancer so, in my son's case, these two items can be eliminated.
42. As somnolence, upper respiratory tract illnesses and fever are adverse symptoms listed for both the Engerix B vaccine and iGAS, I believe that synergistically both of these had a terrible effect on my son, but I have not found any actual diagnosis of 'invasive' group A strep anywhere within my son's records.
43. I have also noticed that the first of my son's blood count results from this hospital admission showed elevated above-range monocytes, but his overall WBC count was within normal range at 10.4. A second blood count taken on 15th July 1989 showed that his WBC had gone down to 7.1, still within normal range.

ANONYMOUS

44. Strep A is usually a fairly mild illness. Bearing in mind that the incubation period before illness is 2 to 5 days, it is very likely that he caught it within the second week after he was vaccinated, but I have no idea where he caught it or who he could have caught it from.
45. I do not recall my son being taken for a brain scan on this occasion. I suspected that it might be a bleed, but his symptoms were not the same as when he'd had brain bleeding in the previous year. He'd not had any seizures at all since his epilepsy diagnosis some 9 months earlier, so this was a bit confusing for me. I was later told that he did not have a bleed so I did not understand why he was being injected with factor VIII on the day he was admitted and the following day. Nobody explained this to me at the time, but I now know that the somnolence he suffered is an indication of brain inflammation.
46. I believe that my son's neurological injuries, which he still suffers with to this day are a combination of all of these neuro-inflammatory incidents. He was born with no neurological problems at all; no epilepsy, no learning/intellectual disabilities, no behavioural difficulties nor any form of autism. He was a bright, very happy, engaging and beautiful little boy. His potential to live an independent life has been ripped away from him and this is not going to change, unless some kind of miracle happens. I hope I have explained fully why my son can not and never will be able to engage with this Inquiry and tell his own story. The fact is that he simply can not understand what has been done to him or how he has been harmed.

ANONYMOUS

47. I had recently been asking the hospital why it was necessary to give my son nine doses of Engerix B vaccine when the World Health Organisation (WHO) states on its website that boosters are not recommended for this vaccine if the recipient has completed the initial three-dose course. I am aware that being from a family of haemophiliacs, we were given this vaccine subcutaneously because intramuscular injections pose the risk of bleeding into the muscle, but I did not understand why nobody would answer my questions about the amount that had been given to my son. Maybe there was something else about this vaccine that they did not want to start a conversation about, for instance, the fact that it contained two neurotoxins at the time in the paediatric dose, 250 mcg aluminium hydroxide and 12.5 mcg thimerosal (mercury derived preservative). The thimerosal-free version of this product only became available after the year 2000. Before the year 2000, my son had already had eight of these doses injected into his body.
48. With regard to paragraph 56 of my first statement where I mention a drop in haemoglobin after vaccination, I have read a few papers which say that aluminium toxicity induces anaemia which is not severe, but a blood film will show changes in the red blood cells such as microcytosis and hypochromia, mimicking the classic symptoms of iron deficiency. Impaired transfer of iron into the bone marrow erythrocyte precursors inhibits the incorporation of iron into heme, hence the drop in haemoglobin. This has happened to my son after each shot which was described to me as just 'iron deficiency' and treated with Sytron, which did not help.
49. As a result of finding this, I am also now researching the cause of the '*severe degenerative O/A [osteoarthritic] changes*' in my son's right elbow which was discovered by the hospital in 2010, but to this day nobody has even approached me to mention it to me. Also why three of my son's teeth suddenly crumbled in his mouth without any tooth decay, the roots remaining in his gums which he had to have removed under general anaesthetic in hospital in October 2021. Again, nobody has even attempted to explain to me how this could have happened. I have been left wondering if his whole skeleton is crumbling and if this is related to metal toxicity.

ANONYMOUS

- 50.** The bottom line is, Engerix B Recombinant Hepatitis B vaccine was given to my son for the sole purpose of preventing hepatitis B infection through the use of contaminated blood products. If the blood products used to treat haemophilia were not contaminated with hepatitis, my son would not have been given this vaccine.
- 51.** Engerix B has never been included in the UK's routine child immunisation schedule, but it was and still is listed on the Selective immunisation programme and Additional vaccines for individuals with underlying medical conditions. It would never have been given to any child as part of the routine schedule. Even if it did prevent infection, it appears that it may have been slowly destroying my son's health in other ways, particularly as he has been given what amounts to three times the amount recommended by the World Health Organisation.
- 52.** Despite receiving this Engerix B vaccine, according to (then) consultant haematologist Dr Blecher, again, my son did not develop a sufficient protective antibody response which is the reason, Dr Blecher told me almost 4 years later, that my son 'needed' to be given 'reduced hepatitis' factor VIII to "wake up" his immune system, as he put it to me. The horrific result of that course of action is detailed in my initial statement in paragraphs 32 and 33 also 51 to 55.
- 53.** I found in my late brother B's records that Dr Dolan had tested him for lupus anticoagulant on 20th January 1992. I have also found in my son's hospital records that Dr Dolan had also tested him for the same thing on 19th October 1992 and 28th October 1993. I am aware that lupus is an autoimmune disease, but I had no idea why they would feel the need to test my son for this. I also know that testing for lupus is not routinely done unless the patient has exhibited symptoms of autoimmunity. B was eventually diagnosed with an autoimmune condition a couple of years before he passed away, but to my knowledge my son has never been diagnosed with any autoimmune disease and both of his tests for lupus anticoagulant were negative. I asked myself, why had these tests been carried out without my knowledge?

ANONYMOUS

- 54.** I first looked at the dates these tests were done. My son's first test was done when Dr Blecher had asked for my consent to allow my son to be injected with reduced hepatitis factor VIII in October 1992. When I repeatedly refused he then told me that my son had not generated a sufficient protective antibody response to the hepatitis B vaccine course he had been given almost 4 years earlier. I believe he said this in order to coerce my consent because he'd had almost 4 years to tell me this, then he lead the conversation with what they wanted to do to my son rather than leading with why they needed to do it.
- 55.** I also believe that the test was done to check whether my son had pre-existing auto-immune disease because the hepatitis B virus as well as the hepatitis B vaccine can and does, in some cases, cause auto-immune symptoms. I did not know this at the time. As the result of this test was negative, I believe they felt it would be safe to go ahead and inject my son with the reduced hepatitis factor VIII.
- 56.** The reaction my son suffered after he was injected with reduced hepatitis factor VIII was so painful and severe he needed to have a total of 3 blood transfusions, one after the other, to replace the blood he had lost. This was on 1st February 1993. On 4th February my son was taken into the operating theatre for an endoscopy, which revealed that he had developed mild antral gastritis and, according to the results slip, 'acute on chronic GI bleed'. Despite all this, the whole situation was passed off to me as simply 'a nosebleed', but he had not had one for a week.
- 57.** I believe that the reaction my son had was an auto-immune reaction which is sometimes seen in hepatitis B infection, exacerbated by the fact that he had previously received hepatitis vaccine which did not work properly for him. This reaction can manifest as vasculitis, in other words, vascular damage.

ANONYMOUS

- 58.** I also believe that this is why my son was given a second course of hepatitis B vaccines, the first of this second course given whilst he was still under general anaesthetic for this endoscopy. It was given without my knowledge. I had been told by Dr Blecher that they did not want to give my son a second course of this vaccine because the first course had not worked as expected, but here they were starting a second course behind my back. I believe they did this because, judging from my son's symptoms, they were concerned that they had infected him with hepatitis B and were attempting to limit the infection.
- 59.** The second and third doses of this vaccine course were given to my son in out-patient clinic. As the Inquiry has heard several times, there was a very friendly, family-type atmosphere within the haemophilia centres and ours was no exception. This is why I allowed my son to be taken away from me by the nurse while I sat and chatted with the doctor. I did not know that while he was away from me he was being vaccinated. Each time he returned he would have a small gift, usually a colouring book and a pack of crayons with a drug company's name on. I believe it was Baxter or possibly Bayer, I can not remember exactly which, but I can remember that it began with the letter 'B'.
- 60.** During and after this second course of vaccines, my son began to suffer with clusters of seizures every two to three months. He did not fall asleep again this time. I believe that was because he was four years older, he was more able to tolerate the vaccine, but I had no idea why this pattern of seizures was occurring at the time. He was prescribed an additional anti-convulsant drug, Sabril (Vigabatrin) for this, but he was kept on it for the next 11 years.
- 61.** The second lupus test was done 9 months after the blood transfusions. It now makes sense to me that they would not attempt to test him again for so long because after he had lost so much blood so rapidly he had to be transfused immediately. Also, because he'd had to receive so much donated blood, testing him at that time would not have produced an accurate result. Therefore, they would have had to wait until his own bone marrow had produced enough of his own blood so that it could be tested.

ANONYMOUS

- 62.** I would also like to point out that when I had brought my son to the hospital after he had vomited up so much of his own blood, his blood test showed that his WBC count was 21.3, the neutrophil count alone was 18.72 (87.9%) which is way higher than the normal range and indicates that his immune system had gone awry again.
- 63.** It appears that the use of reduced hepatitis factor VIII did not end in the 1980s. It continued into the 1990s. My son was not infected by contaminated blood products, but I have told his story because he has been seriously harmed, first by the hepatitis B vaccine to prevent infection from contaminated blood products which resulted in brain inflammation when he was 2 years old. Next, he was given reduced hepatitis factor VIII which caused him to develop auto-immune symptoms and he almost bled to death when he was just 6 years old. On top of that he has also received factor VIII product from two batches implicated for vCJD in 1995 and 1997. None of this should ever have been allowed to happen to him or to anyone else.
- 64.** I would also like to add that I was aware of the 7th and 8th hepatitis B vaccine injections my son received. These were 'boosters' as I recall, given on 1st November 1996 and 25th July 1997. I was present with him when these were given. Until I read his hospital records I thought that he had received five of these shots. I had no idea he'd actually had a total of nine of them.

ANONYMOUS

65. Knowing what I now know about my son's brain injuries, I opposed covid vaccination for him because I feared that he would be harmed or killed. I begged and pleaded with the NHS not to do this, but they ended up taking me to court on 6th May 2021. In their statement they said that my son's neurology consultant, Dr O'Donoghue, had confirmed that none of [redacted]s neurological problems were caused by the MMR vaccine he'd received. I know that can not be entirely true because two weeks after receiving it he became ill and developed a lot more inflammation than he should have which caused a chain of events leading to the blood clot in his brain which was discovered the following week. Then all the stages of unresolved atypical measles infection followed right before he was diagnosed with epilepsy in September 1988. This is a 'process' which does not happen immediately, but within a few months. I have yet to hear from anyone who can confirm that SIRS happens purely because of the bleeding aspect of haemophilia. To my knowledge, this does not happen. Despite this, the court still accepted this as a statement of truth when I believe, logically, it could not have been.

66. He had his first hepatitis B vaccine on 21st December 1988, 3 months after I was informed of his epilepsy diagnosis. Brain inflammation/damage followed two weeks after he had his third shot the following year. So, if we assume that the statement by the NHS is truth, does this mean that the brain inflammation he suffered on this occasion is the cause of his learning/intellectual disability, behavioural problems and autistic spectrum disorder? What was actually happening to my son's brain when he fell asleep for 3 consecutive days? I did send a number of questions to the hospital for Dr O'Donoghue to answer in January 2022. He telephoned me a year later on 10th February 2023 and told me that he had written answers to my questions and sent them to the Trust, but I never received them. He said he would chase this up for me, but to date I have still heard nothing more from him nor from the Trust.

ANONYMOUS

- 67.** The hospital knew that my son was suffering with brain inflammation after the hepatitis B shots and treated him for it. I suspected a bleed, but nobody confirmed anything either way. So why did they not tell me what was really going on? I believe they did this for a reason, but what good reason would they have to withhold the details of something as serious as this from a child's mother? How much more serious did things need to get before I was eligible for information?
- 68.** I have only recently discovered in the past couple of years that the Vaccine Damage Payment Scheme had been set up by the government. Any claim for a child's injury has to be made before the victim reaches their 21st birthday. My son is now 36 years old. So, while my questions were not being answered by medical professionals and they refused to give me his autism diagnosis for 25 years, my son's permanent brain injuries were, for want of a better phrase, swept under the carpet.
- 69.** Since my son went into care in 2005 I have been invoiced every month for his residential placement. So far these invoices have totalled over £70,000. I strongly believe that he would not be in the care system at all if he had not suffered any brain damage. The only thing I blame myself for is that I blindly trusted the medical professionals and did what they advised without questioning.

ANONYMOUS

70. When I asked medical professionals why the information about my son's brain injuries was kept from me, I had either been gaslighted or my questions were simply not answered. Although, during an online meeting in January 2022 one doctor said to me *"we would always expect information to be shared with families and carers and so if that wasn't shared with you, again, I am very very sorry, as I say unfortunately nobody here, nobody working was working at the time so I can't go back directly to the people involved in his care at the time"*. I am aware of this, but this same doctor, as I read out loud some study information I had discovered which explains how people who have haemoglobinopathies (such as sickle-cell disease and trait, G6PD deficiency, thalassaemia etc) have a reduced oxygen carrying capacity when they are under immunological stress, decided to giggle to herself in front of me. I don't know what was so funny about what I was reading. I was trying to explain to her how my son, who also has sickle cell trait, was in severe immunological stress and she found this amusing. Perhaps she forgot that I could actually see her on screen.

71. I asked "I'm sorry, do you find this funny?" She almost immediately responded with "No, sorry?" From this quick reaction she obviously knew that I was referring to her because the other people at the meeting did not respond at all. I now feel that they see us as unimportant collateral damage that should be dismissed as quickly as possible and that they see me as a joke. If the hospital had been transparent with me in the first instance, I would never have had to go through that experience. Thankfully my mother and one of my sisters were present for support because I was emotionally in bits after that meeting.

72. All I want to know is 'how can I protect my son from further harm and help him to live his best life under the circumstances?' In order to do that, I need to know what each episode of brain inflammation did to him. I have made a lot of progress on my own, but unfortunately I can not find anyone in the medical profession who is willing help me fill in the gaps in my knowledge.

ANONYMOUS

73. Anyone would think that the best place to start would be with the medical professionals, but as I have explained, they have not been willing to help. I should not have had to research and study so much to find answers simply because they can not be bothered with me. This has been my life for the last four years since my brother's death and then so soon after that I discovered that all this important information had been hidden from me for over 30 years by people I had trusted so much since I was a girl. I simply sat and cried for a fortnight because I was in shock. I have been left wondering what else they have hidden from me. I hate to say this, but my trust in the NHS is waning more and more every day because of this. Our family has been put through enough heartache. We do not need to be treated like this on top of everything else that has happened.

74. Thankfully the Expert Report on Fractionation published by this Inquiry has been of invaluable assistance helping me to make logical sense of what really happened to my boy. I found information about immunological abnormalities in haemophiliacs on page 73 of this report which prompted me to look into this further and I was shocked to find the large number of studies that have actually been written about this. I had no idea they even existed. You have no idea how much this information has helped. I can not thank you enough.

ANONYMOUS

75. In order to assist the Infected Blood Inquiry further, I would like to provide copies of other documents I hold as regards [B] and [S], these being:-

76. **Exhibit WITN3733011** - A copy of the report written and sent to our local coroner by [B]'s (then) cardiologist, Dr Timothy Robinson

77. **Exhibit WITN3733012** - A copy of the Entresto article published on 12th December 2019 entitled '*Entresto Holds Up In The Real World ... But Not For Everyone – Drug not better than ACE inhibitor, ARB for black patients?*' I emailed a copy of this and the previous mentioned exhibit to investigator, Mr [GRO-D], in June 2021, but just in case you do not have these I have included them here.

78. **Exhibit WITN3733013** - This is a file containing the documents left with us by [B] before he went on holiday to Florida

Pages 1 and 2 - 07.11.18 - A copy of the letter to [B]'s GP from Dr Timothy Robinson suggesting that [B] should be prescribed Entresto.

Page 3 - A copy of the letter to heart-failure nurse, Darren Warrior from Dr Timothy Robinson asking him to oversee the change from Ramipril to Entresto.

Page 4 - A copy of the A&E discharge summary note dated 28 May 2019. This is the last time [B] went to A&E for medical help, two months after starting Entresto.

79. **Exhibit WITN3733014** - A copy of page 92 from [B]'s GP record. This is [B]'s care plan. Towards the bottom of the page under the date 21st March 2019 it states '*as per cardiologist's request, could stop ramipril and commence entresto*'

80. **Exhibit WITN3733015** - This is a document with [B]'s hepatitis B test results from 1986 to 2005. The first indication that he had been previously infected was on 6th January 1987 when he was at Treloars.

ANONYMOUS

- 81. Exhibit WITN3733016** - A copy of a clinical note sheet showing the dates my son S was given his first course of hepatitis B vaccine
- 82. Exhibit WITN3733017** - A copy of A&E admission sheet showing the date and being asleep for 3 days was the reason my son was taken to hospital.
- 83. Exhibit WITN3733018** - A copy of the first page from my son's factor VIII record for 1989 showing that he was treated for an 'intracranial' issue on the same day he was admitted to hospital, 9th July and the following day, 10th July 1989. I was never told why he had been treated.
- 84. Exhibit WITN3733019** - A copy of page 7 from the package insert for the Engerix B Recombinant Hepatitis B vaccine, showing 'fever', 'upper respiratory tract illnesses' and 'somnolence' as a possible adverse reaction to this product. Somnolence indicates brain inflammation / damage in an infant.
- 85. Exhibit WITN3733020** - A PDF file containing five documents showing what was done to my son before and after receiving reduced hepatitis factor VIII:-
- Page 1 - 19.10.92 – Result of the first test for lupus taken before being given reduced hepatitis factor VIII
 - Page 2 - 01.02.93 – blood test results showing Hb 4.4, WBC 21.3, Platelets 600 and 'Acute on chronic GI bleed' which was treated with Cimetidine
 - Page 3 - 01.02.93 – I.V. Prescription sheet showing 3 blood transfusions
 - Page 4 - 03.02.93 – post endoscopy diagram showing damage to the antrum of my son's stomach. The date says 3rd February, but I believe it was the following day, 4th February 1993
 - Page 5 - 28.10.93 – Result of my son's second test for lupus
- Exhibits WITN3733005 and WITN3733006 submitted with my previous statement also pertain to this particular hospital admission.

ANONYMOUS

86. As I had been invited to, I now produce as **Exhibit WITN3733021**. This confirmed another exposure to vCJD from an implicated batch. This was the second of the communications we had with the Haemophilia Unit telling us of my son's exposure. I was unable to locate this letter in time for my initial statement interview and I now present it.

Statement Of Truth

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

Signed :

GRO-B

Dated : 16 August 2023