

Witness Name: Della Ryness-Hirsch

Statement No.: WITN0282001

Exhibits: WITN0282002-048

Dated: 08 February 2019

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF Della Ryness-Hirsch

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I, Della Ryness-Hirsch provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4 September 2018. I have been assisted in the drafting of this statement with input from my husband Dan Hirsch.

I will say as follows: -

#### **Section 1. Introduction**

1. My name is Della Ryness-Hirsch. My date of birth is GRO-C 1944. My address is known to the Inquiry. I am married to Dan who is originally from New York.
2. I intend to speak about my late twin son Nicholas's illness, being infected with HCV, his treatment and subsequent death. In particular, the nature of his illness, how the illness affected him and my family, the treatment received and the impact it had on him, the family and our lives together.
3. I am not currently legally represented and I am happy for the Inquiry investigators to take my statement.

## Section 2. How Affected

4. Dan and I were married in 1972. We met in San Francisco in the 60's where we lived for some time, before returning to England living together for some years before getting married in the UK in the Kensington registry office.
5. On [GRO-C] 1976 I gave birth to non-identical twins, Nick and [GRO-C]. They were huge twins and weighed [GRO-C] each. I had to have a caesarean as they were positioned laterally forming a circle in my stomach and the doctor could not turn them.
6. [GRO-C]  
[GRO C] we decided to have the boys circumcised. We were then living in Shepherds Bush and the circumcision took place at home in early June 1976. Later on in the day of the circumcision Dan's mother (whom had come from New York to help with the twins) went upstairs to check on the boys and she found Nick lying in a pool of blood in his cot and she screamed, I remember I was too overwhelmed to do anything.
7. Dan and my sister, Lynne, took Nick to Queen Charlotte's Hospital, Hammersmith. He was admitted to the children's ward and put in an incubator. I don't remember the name of the children's ward. Members of the clinical team asked if there were any blood disorders in the family. A week later Dan and I were informed by a doctor at Queen Charlotte's that Nick had haemophilia. There is no history of haemophilia in our families. [GRO-C]  
[GRO-C] Nick's haemophilia was apparently a one in a million chance of the disease occurring spontaneously.
8. Following Nick's diagnosis I was in a state of complete bewilderment. He was being treated at Queen Charlotte's maternity hospital, for

haemophilia. The staff there saved his life. At this time Dan and I had no knowledge of haemophilia, other than the historical connection with the Russian Royal family.

9. Nick's medical care was transferred to Great Ormond Street hospital (GOSH) immediately after the discharge from Queen Charlotte's hospital, this was in the summer of 1976. At that stage we thought GOSH was the best children's hospital in the world. It was there that we met a young GRO-C Doctor, Dr Colin Sieff, who explained haemophilia to us. Dr Sieff was someone I really liked and trusted. He is currently head of haematology at Boston Children's hospital in the USA.
10. Dr Sieff explained Nick's haemophilia and we thought we'd just have to deal with it. We were given enough information at the time but we didn't really understand the implications then. It was Dr Sieff who informed us about the Haemophilia Society.
11. We didn't really know what haemophilia would mean in our lives. We were living in Shepherds Bush in our newly bought home, which was barely habitable. We were sleeping on a mattress on the floor at night and running our fledgling business during the day. We split our work week for the first 6 weeks – one of us at home, the other at work. After that Dan built a play space and play house in our office at work and the boys came with us to work until they started at nursery school. Regents Park was within walking distance of our business and one of us would take them up there for fresh air etc. every day. Our business was also near to Gt. Ormond Street hospital.
12. The first time we really became aware of the implications of haemophilia was in the hot summer of 1976 when we had the first serious incident. We had a little yard out the back of where we lived. The deck chair Dan sat on collapsed and a bar on the back of the chair flew up and hit Nick on his face causing quite a bruise.

13. We rushed off to Great Ormond Street. They gave him his first injection. It was an intravenous injection and Nick screamed the place down. Dan and I were both in tears as it was so traumatic.
14. The medical staff said that Nick would be ok and discharged him after the injection. When we got home we laid the twins together on a blanket and they turned to each other and laughed. Dan and I thought, "Ok we can do this" and we just got on with our family life after that. After this incident however, I found Nick bruised easily but we just sewed pads on his clothes guarding his knees and elbows further.
15. We joined the Haemophilia Society shortly afterwards. We contributed to them financially (as we still do) because of the work they do (with newly diagnosed and young families) however, as time went on we felt they failed us especially in recent years because of their refusal to support us with regard to the contaminated blood disaster. Over the years I had worked closely with some of the heads of the Society encouraging them to become involved in the contaminated blood situation once it was understood that there was a problem.
16. In 1978 when the twins were two, my closest friend with whom I had travelled to America originally in the sixties, phoned me from the States. She had remained in the States after I left, had married and was working at a high level as a legal secretary. She asked if Nick was receiving any American treatments and advised me to ask the hospital. During that phone call my friend asked me if, "I knew about American blood". At that time I knew the US collected blood from prisoners and those on 'Skid Row' and that it was not safe to use due to the risks of infection. I exhibit an article from the Catholic University Law Review dated summer 1972 which highlights the dangers associated with professional blood donors within the US (WITN0282002). I hadn't thought that American blood was coming over to the UK until my friend raised the possibility.

17. I have since found out that by 1975 the UK was regularly importing blood products from the US as identified in a letter to Dr Maycock at Elstree Blood Products Laboratory (BPL) from Dr Garrott of Stanford University Medical Centre, dated 6 January 1975 (**WITN0282003**). The letter clearly shows the knowledge associated with the collection of commercial blood.
18. I exhibit a letter dated 1 May 1975 from the then Chief Medical Officer, addressed to all Regional medical Officers which identifies the risk of contracting hepatitis from blood donated from certain geographical areas, including the high risk transmitted by the blood of prisoners (**WITN0282004**).
19. I also exhibit a report from the National Blood Transfusion Service (NBTS) dated January 1980 regarding the implications for the NBTS of an adverse report on the BPL by the Inspectors of Medicines Division. The report states in paragraph 1 that if BPL was a commercial operation then the Inspectors would have had no hesitation in stopping manufacturing at BPL until the facility was sufficiently upgraded to meet minimum acceptable levels. (**WITN0282005**). There is no denying that they knew of the issues and the associated risks.
20. I asked at GOSH during a routine visit if Nick was receiving any American treatments and was clearly told "No" and that his treatment came from Cryoprecipitate. I asked Dr Sieff about Factor products and he said it was a new form of treatment that would revolutionise how haemophiliacs were treated but that all the children would be moved onto it when they reached the age of 4. I told him then and later that we would not want Nick to receive American products.
21. I told Dr Sieff I'd lived in America and didn't think I'd like US blood regardless of whether it was treated or screened. In the US people can sell their blood, so blood is collected from drug addicts and we heard later, even from prisoners. My friend sent me articles, which I just gave

to the doctors at GOSH. Unfortunately I didn't photocopy them. I now know this was an error, but it didn't occur to me at the time.

22. By the time GOSH came to change Nick's treatment from cryoprecipitate to Factor products treatment there was nothing in the papers about contaminated blood (although since that time, I have seen reports and evidence that it was well known at that time that the treatment was contaminated). On the day that Dan and I were told by Nick's doctors that his treatment would switch to "Factor VIII treatment" (around about 1980), I informed them that I would not allow him to be given this treatment.
23. I kicked up bloody murder. I told the medics to keep Nick on Cryoprecipitate and was told that there was not enough available. I was told that there was some cryoprecipitate in Elstree but the supply was not sufficient.
24. Dr Sieff assured me that any factor products given to Nick were perfectly safe and were coming from UK donors. Eventually we had no choice and had to agree to Nick receiving Elstree only Factor VIII instead of Cryoprecipitate. Apparently, there just wasn't the availability of Cryoprecipitate and Nick needed treating. The first dose was administered on 3 November 1980 following an injury to Nick's right knee. He was administered 280 units. **(WITN0282006)**.
25. I have since discovered that the source of blood products was well known within government and health departments around this time. A Parliamentary debate (HANSARD) dated 15 December 1980, discussed the financing of BPL including that one of the main sources of blood and blood products into the UK was from the USA, where they utilise paid donors many of whom were described as drug addicts and drunkards **(WITN0282007)**.

26. An earlier report by Diana Wolford dated 15 September 1980 (**WITN0282008**) identified the knowledge associated with the potential take-over of BPL. The report doesn't specify Diana Wolford's credentials but it clearly identifies the impact a takeover of BPL could have on the wider community due to the dangers related to imported blood.
27. A Sunday Times article dated 1 February 1981, by Catherine Stevens, highlighted the inability of the BPL to produce the required amount of Factor product required to treat UK haemophiliacs. As such Factor products were being imported into the UK from America and as a result children at a specific specialist school were being infected (**WITN0282009**).
28. On 21 January 1985 I read an article in the Guardian newspaper titled 'AIDS and a caring society' (**WITN0282010**). I was so concerned I wrote a letter to the paper explaining my family issues and the problem with American Factor products (**WITN0282011**). I was a bit worried about identifying Nick so I wrote the letter using my sister-in-laws details. My letter was published on 23 January under my sister-in-law's name (**WITN0282012**).
29. The following day I received a phone call from Professor Hardisty who was then the Director of the GOSH Haemophilia Centre. He knew I was the author of the Guardian letter. Professor Hardisty requested that Dan and I came to GOSH for a meeting to discuss the letter. I should point out that my letter was written (as I have already stated) under my sister-in-laws' name in order that Nick could not be identified.
30. My sister in law, Julia Harrison – she was a politician and served on the New York City Council for 16 years. The fact that Professor Hardisty could not have known this name as the signatory of the Guardian letter, yet the contents were so familiar to him that he knew immediately it was me who had written it and thus was able to correctly phone me at work to ask Dan and I to visit him. I think this clearly confirms what I have

written about bringing so much information to GOSH in the early years about contamination – Hardisty knew that it had to be me who had written and had that letter published in the paper whatever the name given at the end of the letter.

31. As requested we met up with Professor Hardisty shortly afterwards. As I recall he basically scolded us, saying, “Mr and Mrs Hirsch, do you not think, that I, in my position, would not be aware of such a thing if it existed in the world? I am telling you categorically, I know nothing of this.” He was referring to the heat treatment of blood preventing the spread of viruses. He also told us that they had tested ALL the children in the GOSH blood unit and Nick was the only one that had not showed signs of the HIV virus. We had never been asked for permission to test and as the testing had been done some months earlier, they certainly had not asked us and then in the event of the results – not informed us.
32. A discussion ensued about how to continue to treat Nick Professor Hardisty told us that new heat treated products would be available some months further and asked if we wished Nick to come into GOSH to basically stay on a ward and in bed until that happened (to protect against bleeds). We thought that not feasible and I asked to think about it overnight. By the morning I had realised that we knew (since Nick had no HIV virus as shown by the test) that all the batches we had had from Elstree where some treatment was left in the bottle (this happened regularly as doses were calculated by weight of the person being treated and sometimes there would be half a bottle here and there returned unused.
33. I wondered whether since we knew that all the ‘left overs’ would be virus free (because they had tested Nick and he was negative) if Elstree would have retained these ‘ends of bottles’. It turned out they had (or so we were told) and this treatment was returned to us and was sufficient for Nick to use until he went on to heat-treatment in the January as Prof. Hardisty had told us.

34. Following our meeting, Professor Hardisty then wrote a reply to my 23 January letter. His letter was published on 31 January 1985 (**WITN0282013**). I felt his published response was somewhat disparaging of Dan and I as parents. As a result I wrote to Professor Hardisty directly on 4 February 1985 putting him right as to the reason for my original letter to the Guardian (**WITN0282014**). After this we always felt the relationship between our family and GOSH staff was difficult.
35. On 9 July 1985, (which was the day before we moved Nick's care) Nick had an appointment at GOSH. This was one of his regular visits. We were informed that Nick was being switched to American Factor VIII as the majority of UK haemophilia Centres were running out. I was livid. We realised we could no longer keep getting Nick's treatment at GOSH so we asked the Royal Free (which was our local hospital after we moved from Hammersmith) to take over Nick's care. They said "yes" and requested we bring his medical notes.
36. We returned to GOSH the same day but they refused to give us the file with Nick's medical notes. I don't remember who it was at GOSH that refused to hand over his records. However, about 2 weeks later a nurse from Great Ormond Street rang me at work and said if we'd like to meet her she would give me Nick's file. She met us in the street. Although I recognised her at the time I can't remember her name now. I took the medical records to the Royal Free. I thought they were complete but I couldn't have known for sure. I don't remember looking through them until we got to the Royal Free as I thought it was the right thing to do. We looked at the notes with the head nurse of the haemophilia department at the Royal Free whose name was Christine Harrington. There was a dated page with tramlines scrawled across, within which was written in large letters, "neurotic mother". I recognised that this entry was from the day I kicked up such a fuss about refusing to allow Nick to be given American Factor VIII in early 1980.

37. I rue to this day that I wasn't savvy and didn't photocopy the notes. I was disgusted by the discussion with Professor Hardisty previously. Although I have since managed to obtain copies of Nick's records from GOSH and the Royal Free, curiously the "neurotic mother note" is now missing from the records.
38. Nick transferred to the Royal Free on 10 July 1985 (WITN0282015), he then came under the care of Dr Eleanor Goldman. I think she was a very good doctor. Over the next five years Nick continued his treatment under Dr Goldman. Dr, (later Professor) Lee became the head of the haemophilia department. During this time it would be fair to say our relationship with Dr Lee deteriorated.
39. On 5 June 1990 Dan, Nick and I attended a review with Dr Goldman (WITN0282016). I have very little memory of this actual visit but apparently on this occasion we also discussed HCV. It is fair to state we had no knowledge of what HCV was and it certainly was not explained to us. Blood samples were taken during this visit but that was a very usual practice. I do not believe we were informed that they were going to test Nick for HCV. We left with the knowledge we would be seeing Dr Goldman for the next review in 6 months' time subject to any other issues.
40. I should add here that GRO-C who had contracted Hep A on his world travels. He came to stay with me and after a couple of months had recovered well enough to continue on his way. I think that because of this I was 'lulled' into thinking that Hep C was in the same category. Since this is what killed Nick, I was (very sadly) mistaken.
41. In early July 1990 we received a letter from Dr Christine Lee dated 9 July 1990. The letter informed us that they had tested Nick for antibodies to HCV on 5 June 1990 and his test was positive (WITN0282017).

42. Nick only ever had Elstree treatment. Great Ormond Street kept him on Cryoprecipitate until November 1980 when he went onto NHS Factor products. The Royal Free agreed he would only have Elstree treatments. While we cannot state with any certainty when Nick was infected we are in possession of a Liver Clinic History Sheet with an entry dated 25 March 1996 which states, 'He has chronic hepatitis C (genotype-1) and he was probably infected in 1980 with first clotting factor concentrates' (**WITN0282018**).

### **Section 3. Other Infections**

43. Nick wasn't infected with anything other than HCV as a result of receiving contaminated blood. However, the infection was catastrophic for him. From diagnosis through to his death in 2012 his health just continued to deteriorate. Eventually on 18 March 2012 after a long battle Nick died of multiple organ dysfunction associated with his haemophilia and HCV infection (**WITN0282019**). He was exposed to CJD (see later notes) when he was forced to continue using treatment which was contaminated.

### **Section 4. Consent**

44. I now believe Nick was being tested at GOSH for both HIV and Hepatitis. I knew they were taking blood samples but we thought they were just routine samples to check his haemophilia levels. We didn't know they suspected he could have been infected with something so serious and weren't telling us. To be honest had they bothered to ask us we would have agreed but we were just not consulted.
45. After we had the argument with Professor Hardisty at GOSH I remember he told us directly that they had tested all the boys on the unit for HIV and only Nick had come back negative. This was the only time we were informed of any testing being conducted, it was in the heat of an

argument so we didn't really take it in. (I refer to this more directly above in paragraph 30).

46. I am aware that when we transferred Nick to the care of the Royal Free on 10 July 1985, Dr Goldman was able to establish that Nick had been tested for both hepatitis and HIV at his previous review, which would have been while at GOSH (**WITN0282020**) again unknown to us. On that date we didn't have Nick's records so she must have contacted GOSH to establish this fact. Dr Goldman didn't inform us of the testing by GOSH.
47. Subsequent to Nick's death I applied for Nick's medical records from both GOSH and the Royal Free. I only received them after a bit of a struggle but at least I managed to obtain them. It took several physical meetings over the course of a month to eventually obtain both sets of records. That is when I first realised entries were missing. I have not been able to trace any testing for hepatitis or HIV within the GOSH records however, within the Royal Free records it is very apparent that Nick was regularly tested for both. For instance on 17 October 1988 and 25 October 1989 he tested negative for both. On 5 June 1990 he was negative for HIV and positive for HCV (**WITN0282021**).
48. I have a copy of a letter from Dr Goldman sent to our then GP at Jackson's Lane Practice dated 22 June 1990. The letter states we were aware the HCV test was being conducted, which I dispute. The letter also states the test was positive and that we had not been informed. I cannot understand why we should not have been informed first. It was nearly 3 weeks later that Dr Lee bothered to inform us by letter. Her arrogance makes me so angry (**WITN0282022**). The letter goes on to state that the result was not unexpected by Professor Lee. However, she didn't feel it necessary to explain anything to us, his parents. Even when we received her letter 3 weeks later she was happy to let the issue wait until the next 6 monthly review.

49. On 14 August 1990 I attended a meeting with Dr Goldman. I wanted explanations. Since obtaining the medical records I have now discovered that they were video recording our meetings. I can't say I was aware of this or that I gave permission for this, but from then on the records seem to indicate this was a regular occurrence (**WITN0282016**). In fact the records indicate we were being videotaped on 19 February 1990 (**WITN0282023**), 24 January 1991, 17 April 1991, 15 May 1991 and 24 July 1991 (**WITN0282024**). I have no understanding as to why they should need to video record our meetings.

### **Section 5. Impact**

50. By November 1990 we became aware that Nick was always tired and didn't look well. Our GP thought he might have had glandular fever. It was suggested we took Nick to see Dr Goldman, which we did on 14 November (**WITN0282024**). Following this Dr Goldman wrote to our GP. I have the letter. There is no mention of HCV as a potential reason for him being constantly tired. Dr Goldman suggested it could be attributed to depression (**WITN0282025**). Despite them knowing that he had HCV they did not appear to link it to any of his symptoms.

51. Nick's health was up and down but by April 1991 we were quite concerned that HCV was impacting on him. In May we discussed Nick's condition with Dr Goldman and it was suggested that the Royal Free would monitor his progress with CT scans of his liver and the potential use of Interferon to treat his HCV. At that stage Dr Goldman recorded there was no evidence to suggest immediate cause for concern (**WITN0282024**).

52. In 1992 Nick was given Interferon to see if it could help clear his HCV. It was proposed as a trial by Dr Lee. He remained on this for a year and although it appeared to stabilise his condition, it did not clear the virus. It was an extremely toxic and unpleasant trial and proved a difficult year for him. It was very debilitating and like he had the flu for 12 months and

he was never well during that time. It is sufficient to state he didn't want to go through it again.

53. Medics at the Royal Free continued to monitor Nick after his first course of treatment failed. In June 1996 Nick was contacted by Dr Bhagani from the Royal Free who informed him that they were ready to try Nick on a combination therapy of interferon-alpha and ribavirin to treat his HCV. Nick discussed the options but by July 1997 he still wasn't convinced enough to proceed due to the expected side effects.
54. I was increasingly concerned about the purity of the treatment Nick was receiving for his haemophilia and had on several occasions requested that Nick was switched from his usual Factor product to Recombinant Factor as research was showing it was much safer. I was always told there was no danger from his current treatment, however, it was becoming obvious that there were two different classes of haemophiliacs developing. There were those already infected with HCV who were kept on their present treatment and the newly identified, who were receiving Recombinant. Clearly there were still worried about the treatment Nick was receiving or else they would have been giving it to the new haemophiliacs. Instead they got the Recombinant.
55. In August 1996 I wrote to Dr Lee regarding the current Factor products that Nick was receiving. I asked whether he needed to be vaccinated against hepatitis A and to be informed of the options for the treatment of his HCV. While Dr Lee answered our questions in a letter dated 19 August 1996, she finished by informing us that as Nick was then over 18 years of age, that she could no longer discuss specifics of his medical condition with us (WITN0282026). After this we had to rely on Nick to keep us informed as to what was going on with his health.
56. I should state at this point that it was announced that all haemophiliacs under 18 would be switched to recombinant heat treated safe treatment. Nick at this time was 18 plus 2 months. They refused to give it to him. I wrote to Alan Milburn who was Health Secretary at the time to ask him

for this and to explain that it was torture for Nick to have to continue to treat himself with Factor that he already knew was in part contaminated. Alan Milburn refused and later (see next paragraph) Nick was informed that he had been exposed to CJD in a contaminated batch. During this period, we were contacted by several haemophiliacs who were having 'pure' treatment around the country who offered to 'share' the pure stuff with us. This proved too dodgy and difficult. Nick was terrified every time he had to inject himself until the so-called 'safe' treatment became available for all.

57. In late November 1997 I contacted the haemophilia department's social worker GRO-D. She used to sit in on our consultations with the doctors. I was becoming increasingly concerned regarding news coverage on new variant CJD (vCJD). I was worried that Nick would see this and we wanted to understand the issues first. GRO-D informed me that Nick had been exposed and that the hospital they were in the process of writing to Nick to tell him. I was livid. I managed to request they delayed sending the letter until the following week as Nick was due to play a gig (he was in a band) and we didn't want him to know before he played so that he could enjoy the experience. We needed to be prepared for when he found out.
58. The following week in early December 1997 Nick went to his usual clinic appointment and was called into an interview room where he was told the news very bluntly by one of the doctors. He was also given a letter dated 2 December 1997 from Professor Lee explaining that he had been exposed to vCJD. It was explained that in 1995 an 8Y Factor batch ref FHB4419 had been administered to Nick, which had been potentially contaminated with vCJD (**WITN0282027**). They did not provide any further explanation.
59. Since gathering Nick's records we have discovered that the letter followed a product recall by the Blood Products Laboratory (BPL) on 30 November 1997. The product recall from BPL clearly indicated the donor whose blood had helped create batch FHB4419 was infected with vCJD.

The BPL document clearly states to not inform patients of the reason for the recall (**WITN0282028**).

60. It also appears that Nick was exposed to vCJD in 1994 as a result of a look back exercise conducted in 2004 (**WITN0282029**).
61. Around this time we received a letter from the Haemophilia Society, which included a letter from the Chairman of the UK Haemophilia Centre Directors' Organisation (UKHCDO). These letters explained there was no real risk associated with vCJD and Factor products (**WITN0282030**).
62. When Nick received the news he was devastated. He phoned Dan and I at work and I remember him saying, 'You will never believe what they have given me now'. We tried to calm him and said we would pick him up but he hung up on us. We went home and when Nick eventually turned up he was very angry and was kicking furniture around the house.
63. We made an official complaint as to how Nick had been informed and he received an official apology from the doctor and from Professor Lee.
64. Following this I was more determined to ensure Nick was receiving the best possible treatment for his haemophilia. My sister, who became our (and Nick's) local MP for ten years and who was later to become Baroness Featherstone, started lobbying MP's on our behalf. She wrote to local Health Authorities and to Simon Hughes MP regarding Recombinant Factor VIII not being available to haemophiliacs who had already been infected with either HCV or HIV (**WITN0282031**). I had some time prior when Barbara Roche, who had been our local MP prior to my sister, went to see her urging her to write to Frank Dobson MP regarding these issues (**WITN0282032**). We felt it important that haemophiliacs were not still being exposed to potentially contaminated blood products. No response was received as far as I was made aware.

65. Obviously we weren't the only people campaigning at this time as I have a letter to the Chair of the Haemophilia Society from Frank Dobson MP, the then Health Minister, dated 26 February 1998 regarding the provision of Recombinant Factor FVIII and the effects of vCJD. He finishes by stating that imported non-UK plasma was going to be used to manufacture a range of blood products, including Factor VIII. It is also apparent that he was giving consideration to a special payments scheme for haemophiliacs infected with HCV through NHS treatment **(WITN0282033)**.
66. In August 1998 I wrote to Dr Ludlam from UKHCDO regarding the availability of recombinant factor products. He responded in September 1998 explaining that the issue was a shortage of supply **(WITN0282034)**.
67. Throughout 1999 and 2000 we kept up the pressure with the Royal Free and government ministers regarding Recombinant Factor VIII. Nick really struggled with the knowledge that he could have been infecting himself with other viruses every time he injected himself following a bleed. As such, we felt it necessary to keep up the pressure on health departments to provide Nick with the much safer Recombinant Factor. But nobody was prepared to supply it unless you were a new patient and uninfected. We tried to get Nick supplied on an individual named basis by approaching both his local health authority along with the Royal Free. However, this proved unsuccessful. The response always came back to a shortage of supply **(WITN0282035 & 6)**.
68. In March 2001 the UKHCDO issued advice on managing the shortfall in Recombinant Factor products. Unfortunately their advice was that patients already on plasma-derived products would not be switched until there was a more secure supply **(WITN0282037)**. This news, given to us by Professor Lee in a letter dated 5 April, was very difficult for Nick as he was desperately trying not to inject himself with any plasma products as he didn't trust them. He was advised to inject three times per week on a prophylactic basis to protect his ankles from further deterioration but he

chose not, to because of his fear of contaminated product, which in turn caused real problems with his ankles as a result of the bleeds.

69. We received a very poor response to our applications to the local health authorities who stood by the UKHCDO advice. We had tried to get Nick treated as a named patient. In the end we commenced a legal action with the aim of forcing a change in attitude towards those already infected by plasma-derived factor products. Unfortunately this proved very expensive and we couldn't meet the costs without legal aid. We did receive partial funding but it was never enough to pursue the judicial review we were seeking. We did receive legal advice but it was not supportive in building a case to get Nick the treatment he wanted **(WITN0282038 & 9)**. As such we eventually had to abandon this course of action.
70. In September 2001 Nick wrote a letter explaining his personal perspective on being refused recombinant to Professor Lee in the hope it would help expedite the process. **(WITN0282040)**.
71. During the early 2000's we also pushed to get Nick a new form of treatment, a combination therapy of Pegylated Interferon and Ribavirin for his HCV which was due to be agreed for use by NICE. It apparently was showing good results and was potentially going to be trialled.
72. In late 2001 Nick commenced a second course of treatment for his HCV. He was placed on a combination of Pegylated Interferon and Riberviron which finished around September 2002. We were pre-warned that the treatment was extremely toxic and that there would be unpleasant and disabling side-effects.
73. It all seemed so crazy. He was infected with a debilitating virus by a treatment for something he was born with. He then commenced a treatment for the second time with the understanding that it was going to make him unable to function properly, while living with the knowledge

that he was being refused the very products that could ensure he wasn't going to be further infected with a new virus.

74. The treatment was again very gruelling. He cleared the virus by three months but continued through to the end of the course when he again tested clear. However, to get a true test result he had to spend six months without any treatment and then be tested again. He was unwell several times even after he finished the treatment.
75. One of the side-effects of the treatment was neutropenia (a low neutrophil count affecting Nick's immune system). This meant he had to inject himself twice a week in the stomach with Neupogen to keep his immune system strong. Needless to say he was always on antibiotics.
76. In March 2003, some six months after finishing this course of treatment, Nick was tested again. The HCV had returned although his liver function at that time was considered to be within normal levels. A decision was made by one of Nick's Consultants, Dr Ty Ty Yee, to keep reviewing him every 6 months (**WITN0282041 - 43**).
77. Nick was again devastated and went into quite a depression. He was convinced he had something really wrong with him outside of the HCV. By this time Nick was developing a real phobia of doctors and hospitals. He felt every time he met with a doctor they just gave him bad news. It was somewhat justified as yet again he was sent away with nothing more than 'we will review you in six months' time'.
78. Eventually on 21 August 2003 Nick was moved over to Recombinant Factor VIII. We were advised that he was receiving the Recombinant earlier than expected due to our interventions. It felt like a victory, we had been fighting for this for eight years. Who knows what else he was exposed to in all that time? Throughout Nick's treatment we had continued telling the doctors of the dangers but they just weren't listening. I understand Recombinant became generally available in late January 2004.

79. Nick remained at the Royal Free for several years after he was given Recombinant Factor. However, he lost faith in the hospital even though they continued to treat him with 'Fibro scans' of his liver as well as a biopsy. During this time Nick got to know Professor Foster, a consultant at the Royal London Hospital, Whitechapel. He really took to him and in October 2009 he transferred his care across to Professor Foster (WITN0282044).
80. I first met Professor Foster in December 1999. I had attended a conference regarding HCV where Professor Foster was a speaker. He was trying new forms of treatment. At that stage I was very impressed with him. In January 2001 we had an appointment with Dr Foster at St Mary's Paddington, although Nick's care remained at the Royal Free until his official transfer in October 2009.
81. Nick trusted Professor Foster and after his disappointments with the Royal Free, arranged for his care to be moved across to the Royal London Hospital under the care of Professor Foster. Nick liked Foster and Foster seemed to be the only person in the medical world who behaved like a human being to his patients, but we were wrong.
82. Professor Foster had his own way of working. He didn't believe in Fibro scans. I cannot underline how important this was because we were unable to press Professor Foster into giving Nick a Fibroscan, he was unaware as to how bad Nick's liver had become. Had Nick been given a Fibroscan, we believe that the course he had been put on to 'cure' him would have been stopped and we could have saved him. Professor Foster started to regard Nick as a 'specimen' because he was on this terrible treatment and was suffering so many awful side effects.
83. Professor Foster informed us he had attended a conference in Japan where he discussed Nick's condition as being the "worst affected" of all those he had treated. However, he still refused to give Nick any Fibroscans. Had Professor Foster given Nick a Fibroscan he would have

seen the condition of his liver. I tried to get a private trial of a new treatment for Nick but Professor Foster refused to allow it.

84. Professor Foster eventually put Nick on another trial to beat his HCV but it had terrible side effects. Nick never complained. His partner Olga would bathe his legs and apply cream, he had sores all over his body. Professor Foster still refused to use a Fibro scan even though I told him that I thought Nick's liver was deteriorating. I even suggested putting Nick on the liver transplant list but he didn't feel Nick was ill enough. Professor Foster wouldn't have it, he would just send Nick to the dermatology unit and we would sit there for hours with Nick in excruciating pain.
85. Professor Foster had a team of doctors working for him. On one occasion the doctor treating Nick wanted to do a skin biopsy and I questioned the decision. I don't remember the doctor's name but I had to inform her that Nick was a haemophiliac. I couldn't believe it when I was told his notes didn't have that recorded.
86. Nick's health continued to deteriorate. The day before Nick went into hospital for the last time he was really bad. He was in a lot of pain but wouldn't complain. We suggested going to hospital but Nick didn't want to go as he still had confidence in Foster.
87. My best friend who had been so vigilant in San Francisco and had been the person who had originally alerted us to the blood contamination had recently died of cancer and we went to her memorial in America. When we came back Nick was definitely worse. We went to Professor Foster and I said I was really worried. He said something that indicated his liver was bad. We were still not sure what to do. I thought he had cleared the virus but it didn't really matter because it was all too late for Nick.
88. The next day Nick deteriorated and was taken into hospital. He died three days later in the Intensive Care Unit (ICU) at the Royal London

Hospital on 18 March 2012, leaving behind his partner of 12 years and a baby daughter of 10 months.

### **Section 6. Treatment/Care/Support**

89. The treatment Nick received at Queen Charlotte Hospital immediately after his haemophilia diagnosis was good. He was then transferred to GOSH and in the first instance his treatment appeared to be very good when he was under the care of Dr Colin Seiff. However, the more I tried to inform GOSH of the dangers of American products the worse our relationship with the medical staff became. This was in terms of the way they were insisting on treating Nick with products that we felt were detrimental to his health. GOSH failed to take my concerns seriously about the products being given to haemophiliacs. As far as the American newspaper articles, which I had been sharing with the unit were concerned, these products were not free from contamination and when I questioned their processes we were subjected to unjustified criticism by the head of the Haemophilia Centre.
90. When we decided to move Nick from GOSH to the Royal Free, GOSH initially refused to release his medical records. When they were released I believe this was done without the authority of the doctors. I found that I had been branded a "neurotic mother" which was written within big tramlines across Nick's records. It was so obvious that my concerns had not been taken seriously.
91. Once at the Royal Free Nick, had good care until Dr Goldman retired. His care was then taken over by Doctor Christine Lee who later became a Professor and head of department. I became aware of the benefits of recombinant factor in 1996. It was so obvious that there were two distinct groups of haemophiliacs. The young untreated haemophiliacs were given recombinant factor, while the older already infected, had to receive the plasma derived products. This was discrimination based upon availability. Availability was only an issue because of cost and the

amount the government were willing to invest. This was not right. We had to fight for nearly eight years before Nick received recombinant factor.

92. This was about all of the infected people, not just Nick. They were so harsh saying some could have a trial and some couldn't. We offered to pay privately for the treatment for the one young patient who was not going to be on the trial but the Royal Free responded with fury. Dr Lee went ballistic. I wrote to health authorities, ministers, to health secretaries and to the Home Secretary. They had my child's life in their hands so I pushed as far as I could. You are so vulnerable when you are fighting with the authorities.
93. We are very aware that Nick was exposed to vCJD in 1994 and 1995. It is very possible that he was being exposed to other viruses as well as vCJD during the eight years we were fighting. Nick had a much weakened immune system. We have no way of knowing whether he was being re-infected or exposed to the further risk of HIV.
94. On one occasion Olga rang from the Whittington Hospital to say that Nick was in pain in casualty and she felt they both needed our support. We went there and I said to the doctor that I wasn't sure if Nick's symptoms were to do with his haemophilia or something unrelated. I told them that he needed to go to the Royal Free quickly. The doctor asked who I was and I told him I was his mother, he said, "Oh, his mother." He was so rude.
95. The Whittington Hospital linked Nick up to a machine in the A&E department and the tests showed he was dying. I said I was ringing the Royal Free, they didn't want Nick to go, but they gave me a phone and the Royal Free sent an ambulance over. It transpired he wasn't dying, their machine was defective and it turned out he had gallstones.
96. I wrote and complained directly to the Whittington hospital about how dismissive of me the doctor was and for using a defective machine that

gave such worrying results. I have always said that there needs to be a fast-track process for haemophiliacs as you just don't know what you are dealing with in an emergency.

97. The day Nick was admitted to hospital for the last time, Olga and I spent an hour each trying to get an ambulance but the emergency services wouldn't send one. We told them he was a haemophiliac and we thought his liver had failed but they still didn't send an ambulance.
98. We were so frightened that we paid for a private ambulance and it appeared that the ambulance crew had limited medical knowledge. Dan travelled with Nick in the ambulance. I followed in our car with Olga, the baby and her parents. We got him to the Royal London where he was swiftly admitted to a specialist emergency unit.
99. Nick was in terrible pain. He had sepsis but the medical team didn't seem to recognise it. Nick was given morphine, which calmed him down. The staff told Olga and I to go and get some tea. Then they said they'd get him to intensive care and then we could go up. When we went up to intensive care we were kept waiting 15-20 minutes.
100. They wouldn't let us in so we slept on the floor outside the ward. My sister Lynne came to stay at the hospital with us, she got special permission from Parliament as they were sitting and she would not normally have been permitted to just leave.
101. The next morning a male nurse came out and told us we could go in and see Nick. He especially emphasised that Nick was sedated as he had been so distressed during the night. The nurse was so sadistic the whole way through. He was so rude to Olga. We informed the staff that my sister (who was standing there with us) was an MP. It was only then they offered us a room. I said "...and you wouldn't call us when you knew he was so distressed, his own mother and family? You could have woken us up when we were on the floor to tell us our son was so

distressed so that we could come in to comfort him.” Instead they chose to leave us outside the unit, sleeping on the floor and not inform us sedate him instead. Nick must have been so frightened. We never saw him alive again. There was no hope but we asked them to wait before disconnecting him from life support until his twin and his partner could get to the hospital. It haunts me.

102. Nick died on 18 March 2012 at the Royal London Hospital and the medical system had screwed us from the beginning to the end. They experimented on him and denied his family comfort. We did complain via the hospital Patient Advice Liaison Service (PALS) but it went nowhere. I felt this was a completion of the lies and the cheating and the way commercial interest from the beginning to the end applied to all of this. After all money is everything as precedent is showing. To me it is clear that commercial interest was at the heart of everything that went on.

103. The pastoral care throughout was terrible when delivering bad or difficult news. Families like ours have had to struggle against faceless bureaucracy for so many years with very little encouragement or care. We found clinicians very resistant to involve us as parents in any choices.

### **Section 7. Financial Assistance**

104. I don't believe Nick received much in the way of financial support while he was alive. He applied for help from the Skipton Fund in June 2004 (WITN0282045). I seem to remember he received a one-off payment which was quite large which was paid by the government. That was all.

105. Nick also applied for disability payments as he was sometimes incapacitated and needed a wheelchair. The bleeds into his ankles created real problems for him. In 2001 Nick was assessed and awarded benefits. In 2003 he was reassessed and they turned him down as he was apparently receiving £8.70 a week too much although his

circumstances hadn't changed (**WITN0282046**). He did, however, manage to get a car through 'Motability' which helped improve his independence.

106. After his death Nick's partner eventually received a payment of £50,000 through the Skipton fund. This was after quite a fight and was paid to her in late 2012. I applied on Olga's behalf and the person I talked to when I gave details said to me 'Oh so you want charity'. I was so furious that I reported this to a variety of people by letter. They also told me that as a partner (not wife) she was not entitled to this. I investigated and found a law in the Social Benefits law that showed that it had been decided that Social Security would be paid to a couple living together but not married because it would cost the DHSS less money than paying them as separate individuals, I thought this should apply to Nick's case as well. I wrote to my sister (She was MP to us and to Nick and Olga at this time. I gave her the Social Security law details and she took it up as we were her constituents, our case was accepted and Olga got the money. We had to prove her relationship to Nick or else they wouldn't pay. She received an additional £10,000 in April 2017.

107. We attempted to get payments from the Caxton Foundation in 2012 but that proved impossible. We applied and wrote many letters but we were not able to secure any payments for Nick's partner or daughter other than a small amount here and there. There are real problems with a charitable system that is run by heads of the very organisation that has caused a person's death we were told at later All Party Parliamentary Group (APPG) meetings that the Trusts were staffed by ex NHS employees. We have also been told that the current DOH Business Trust has any employees of the disgraced Trusts who wished to transfer over. There needs independence and a clear indication that there is no possible conflict of interest on the part of any person tasked with running the funds.

## Section 8. Other Issues

108. During 2000 to 2003 I wrote in excess of 50 letters to Barnet NHS Trust regarding recombinant factor. I received around 20 replies all of which were very bland and negative. There was zero interest with no intention of taking my application to a Complex Appeal Procedure. The head of the Haemophilia Centre at the time wouldn't support our application. We had a stormy relationship due to what she saw as my unwarranted oversight. As parents we only wanted what was best for Nick and had to fight all the time.
109. In later correspondence all responses I received failed to address the points made and questions asked. No one was prepared to act despite the fact that the government of the day, together with some of the haemophilia clinicians, had been fully aware of the dangers as they developed as I maintain they had been with HIV, HCV and vCJD.
110. We believe that Nick died because the so-called 'approved' treatment for HCV, Telaprevir and Ribavirin killed him or at the very least made worse the unknown liver damage caused by the HCV. No one was reported as having died during the previous years of worldwide trials of these drugs but after Nick died, we now understand that deaths had actually occurred worldwide (**WITN0282047**).
111. In 2006 the department of health produced a policy and guidance regarding the self-sufficiency of blood and blood products within the UK. This report has since been withdrawn as deemed no longer accurate. When written it was used as a means of rebutting any claims that self-sufficiency would have prevented HCV.
112. However, even though withdrawn government ministers continued to argue that self-sufficiency was not an issue and continually referred back to the withdrawn article to support their arguments. We have a chain of communication highlighting this issue and how the government

minister involved has had to back down and offer a retraction (WITN0282048).

113. On 11 July 2007 I attended the Archer inquiry and gave oral evidence explaining what had happened to Nick up until that point in time. As far as I am concerned my evidence has not changed except, the full severity and extent of Nick's infection and appalling treatment is now known.

114. Finally I would like to emphasise the emotional impact of finding out that our son had been treated with contaminated blood products and had contracted HCV from which he died. Additionally, as this witness statement shows, having lived in the US, I fought with all I had, to bring my knowledge of the dangers of American blood products to bear. I had not realised this contamination extended to Elstree Blood Laboratories.

115. Despite and because of the long battle for recognition and proper treatment, through which one had to remain strong and determined, we failed to save Nick. When he died, the emotional strain and misery that was caused to Dan and I, to his twin brother, to his partner of 12 years and the sadness that was yet to be realised by his daughter, who was only ten months old at the time, should never be underestimated. I consider myself to be a strong person but this decimated me. I still feel terrible that I wasn't able to save Nick.

### **Statement of Truth**

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

GRO-C

Signed

Dated 8th February, 2019

**Exhibits utilised in the creation of this statement are as follows:**

<b>Date</b>	<b>Notes</b>	<b>Exhibit</b>
01/06/1972	Marc Franklin article: 'Hepatitis, Blood Transfusions and Public Action'	WITN0282002
06/01/1975	Letter to Dr Maycock re Factor VIII and IX	WITN0282003
01/05/1975	Letter re Blood Donation and Hepatitis	WITN0282004
15/09/1980	Report by Diana Wolford	WITN0282008
Jan 1980	Chairman's report re conditions at BPL	WITN0282005
28/10/1980	Medical records extract FVIII 280 units given for first time	WITN0282006
15/12/1980	Hansard debate	WITN0282007
02/03/1981	Sunday Telegraph article: 'Ten sick after Factor 8 doses'	WITN0282009
21/01/1985	The Guardian article: 'Aids and a caring society'	WITN0282010
21/01/1985	Letter from Julia Harrison re haemophiliac son	WITN0282011
23/01/1985	The Guardian article: 'Bad blood that leads to an Aids dilemma'	WITN0282012
31/01/1985	Guardian article 'Overheated Blood' by Prof Hardisty GOSH	WITN0282013

04/02/1985	Letter from Della to Professor Hardisty re response to letter in the Guardian	WITN0282014
10/07/1985	Consultation note transfer to Royal Free from GOSH. Records Anti HTLVIII negative when tested at last review, HBsAg negative.	WITN0282020
10/07/1985	History sheet. Treated at GOSH until 10/07/85. Home treatment since 1982. Heat treated FVIII (NHS) since March 1985	WITN0282015
17/10/1988	Haematology report Hepatitis Neg	WITN0282021
25/10/1989	Haematology report Hepatitis Neg, HIV Neg	WITN0282021
19/02/1990	Seen at request of mother – videotaped. Joined by RM and father for later part of interview.	WITN0282023
05/06/1990	Haematology report Hepatitis C Poss, HIV Neg	WITN0282021
05/06/1990	History sheet, discussed anti HCV with Mr Hirsch	WITN0282016
22/06/1990	Letter Royal Free to Dr Riddell GP. HCV test positive. Family not informed. Most Haemophiliacs treated with FVIII have been infected with NANB hepatitis. Result not unexpected.	WITN0282022
09/07/1990	Letter Dr Lee to Mrs Hirsch informing of positive HCV test result on 05/06/90	WITN0282017
14/08/1990	History sheet, follow up, videoed, wants an explanation.	WITN0282015
14/11/1990	History sheet, Nick off colour and very tired, GP suggests Glandular Fever. Bottom of page see video tape for details.	WITN0282024
27/11/1990	Letter from Dr Goldman to GP re Nick being constantly tired. Considered to be depression. No reference to HCV.	WITN0282025
17/04/1991	History sheet. Came to discuss HCV. Videotaped.	WITN0282023
15/05/1991	History sheet. Mr & Mrs Hirsch discuss HCV, very distressed following report in Sunday Times. Interview videotaped.	WITN0282023
06/11/1995	vCJD report FHB4419 NH first dose	WITN0282029
25/03/1996	History sheet Liver Clinic from date to 13/12/04. Has chronic HCV and was probably infected in 1980 with first clotting factor concentrates.	WITN0282018
19/08/1996	Letter from Christine Lee re Alpha factor VIII	WITN0282026

30/11/1997	BPL product recall due to vCJD batch FHB4419 exp 06/06/98. Letter dated 31/10/? From Royal Free Hospital stating Nick Hirsch received batch FHB4419 in 1995.	WITN0282028
01/12/1997	Letter from the Haemophilia Society re Recombinant/ Blood Products and New Variant CJD	WITN0282030
02/12/1997	Letter from Professor Christine Lee to Mr Hirsch re CJD.	WITN0282027
03/12/1997	Letter re Treatment for Haemophiliacs	WITN0282031
03/12/1997	Letter from Lynne Featherston re Treatment for Haemophiliacs	WITN0282031
10/12/1997	Letter from Simon Hughes MP re safe treatment for haemophiliacs	WITN0282031
18/12/1997	Letter re Treatment for Hepatitis	WITN0282031
26/01/1998	Letter from Lynne Featherstone to Ms Outram re Hornsey Central Hospital and Haemophilia	WITN0282031
16/02/1998	Letter from Barbara Roche MP to Ms Ryness-Hirsch re Frank Dobson	WITN0282032
26/02/1998	Letter re Hornsey Central Hospital and Haemophilia	WITN0282031
26/02/1998	Letter from Frank Dobson	WITN0282033
20/05/1998	Letter from Barbara Roche MP	WITN0282030
25/08/1998	Letter from Della re Recombinant Factor VIII	WITN0282034
24/01/2001	Letter from Christine Lee re Pegylated Interferon and Ribavirin	WITN0282035
29/01/2001	Letter from Della to Ms. Chambers re request for Recombinant Factor VIII	WITN0282036
05/04/2001	Letter from Christine Lee re Effects of Bayer ceasing to release Recombinant Factor VIII	WITN0282037
11/09/2001	Statement by Nick Hirsch	WITN0282040
09/05/2002	Email re Jonathan Glasson	WITN0282038
24/06/2002	Irwin Mitchell Medico-legal Report	WITN0282039
04/04/2003	Letter from Ty Ty Yee re Hepatitis C	WITN0282041
04/04/2003	Letter from Royal Free HCV relapse 6 months after stopping treatment.	WITN0282042
14/04/2003	Letter from Della re Nick <b>GRO-C</b>	WITN0282043
17/06/2004	Skipton Application	WITN0282045
11/10/2009	Letter from NH to Royal Free. Decided to transfer care to Royal London under Proff Foster.	WITN0282044
18/03/2012	Death Cert NH inc Hepatitis C.	WITN0282019

29/08/2017	Email chain Baroness Featherstone and DH regarding the Haemophiliac community continually being rebuffed using evidence from the 2006 report	WITN0282047
18/04/2018	Appeals Service	WITN0282046
2012	Deaths from Telaprevir	WITN0282047
Jan 2017	Evidence that self-sufficiency report is still being used	WITN0282048