Witness Name: Patricia Burns
Statement No: WITN1126001
Exhibits:WITN1126002 - 5
Dated: December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PATRICIA BURNS

I, Patricia Burns will say as follows:-

Section 1. Introduction

1. My name is Patricia Jean Burns and my date of birth is GRO-C 1937. I live at GRO-C. I am the surviving spouse of Brian Burns, born on the GRO-C 1936, deceased 11th April 2001.

2. My husband Brian passed away on 11th April 2011 after contracting Hepatitis C (Hep C) from infected blood products on an unknown date. The Hep C went on to cause both cancer and cirrhosis to his liver leading to liver failure and his death at the age of 64.

3. Since his death, I have lived alone at the above address. I have two sons, Philip Albert Burns and Andrew Brian Burns both living away from the area in GRO-C and GRO-C respectively.

4. This witness statement has been prepared without the benefit of access to my late husband's full medical records.

Section 2. How Affected

5. Brian's medical records have been destroyed and as such I am unable to give full details of when he was infected. I am able to provide details of his attendance and blood products given to him as well as some dates when he had blood tests. I requested and received this information in September 2011, from the National Haemophilia Database (NHD) which is exhibited at WITN1126002.

6. When I met Brian in 1959, he informed me that he had a mild form of Haemophilia. He was diagnosed as a child, when he had a tooth extracted and the bleeding would not stop. He told me that his mother usually took him to the hospital for treatment. In subsequent years, we made many visits to Manchester Royal Infirmary, some of them more urgents than others and Brian was given blood clotting agent to stop his bleeding. Again, without his medical records I can only confirm this through the NHD exhibited at WITN1126002.

7. I do not recall the exact date, but I believe Brian received Factor VIII (FVIII) blood products as soon as they became available to him at the Manchester Royal Infirmary. Prior to this, he would attend the Manchester Royal Infirmary for blood transfusions when he had a bleed, this would usually take a few hours and then we would return home straight away.

8. We did not administer any FVIII at home, Brian was always treated for bleeds at the hospital. As Brian had always lived in the Manchester area, he received nearly all of his treatments at the Manchester Royal Infirmary. From what I remember he was only treated for a bleed outside of this country once, whilst we were on holiday in Spain in or about 1976/77. This ended badly and we were flown home early and taken to Manchester Royal Infirmary for treatment. On one occasion, he also attended our old hospital, Bury General Hospital, where again he was moved to Manchester Royal Infirmary to be treated correctly.

9. Whilst at Manchester Royal Infirmary, Brian was seen by many doctors and consultants, but I am not able to name them all. I am however aware that in or

about 1993 the Department of Clinical Haematology was staffed by the following Consultants: R.T. Wensley, J.G. Chang, E.M. Love, J.A. Liu Yin, G.S. Lucas, K.H. Shwe, with K.I. Cinkotai being an Associate Specialist and C.G. Geary being the Director this is exhibited at WITN1126003.

10. In or about 1993, Dr Lucas was the acting Haemophilia Director/Consultant Haematologist and Dr Warnes was a Consultant Gastroenterologist at Manchester Royal Infirmary. I can also confirm that from 2004 my correspondence with Manchester Royal Infirmary had been from Dr Hay.

11. It has been some time since Brian's death and even longer since the news was broken to us that Brian had been infected with Hep C, so I am unsure as to the exact date or if the news was ever broken to us before 1993. I recall that we were both in total shock and devastation when, in October 1993, we received a letter stating that Brian's liver was not working as it should, due to his previous infection with Hep C. This letter has been exhibited at WITN1126003.

12. At this point Dr Lucas and Dr Bolton were available for any questions we had. I cannot recall what we did with regards to this, or when and what happened at our subsequent appointment with Dr Bolton following the letter exhibited at WITN1126003.

13. I believe the manner in which we were informed was terrible. We were not given any information and we had to chase the medical professionals for answers. I recall asking whether Hep C was contagious and we were told by the doctor that it was not.

14. I believe that it was at one of Brian's many visits to the Manchester Royal Infirmary and his treatment with FVIII that he was infected with Hep C, which lead to him developing both liver cancer and cirrhosis. However, I am not able to say exactly when or with which batch he was infected.

15. I do not recall being given any advice regarding the risk of infected blood products whilst attending any treatments or transfusions. The first recollection of being given any form of advice about Hep C was sometime after July 1994,

and it took the form of an A4 sheet of paper titled 'Hepatitis C Virus; What we all need to know', which is exhibited at WITN1126004. I believe it was from the Manchester Royal Infirmary, but sometime in 1994 and not 1993 as I have annotated on the exhibit.

16. Despite the earlier advice that Hep C could not infect others, the leaflet exhibited at WITN1126004 contained information on the risk of Hep C being passed sexually and as such I have had a number of blood tests to confirm I have not contracted Hep C. A record of some of these tests can be seen on my Hospitalisation and Serious Illness Record which is exhibited at WITN1126005. Whenever I was tested for Hep C it was always negative.

17. As previously stated, my first recollection of finding out that Brian was Hep C positive was from a letter we received in October 1993, stating that previous infections by Hep C caused liver problems and we were to go see Dr Bolton. I do not recall any information being given to us prior to receiving the above letter and do not remember the conversation that took place in this consultation with Dr Bolton.

18. I believe that the information that we were given was inadequate as I clearly remember our horror, shock and disbelief when we received this letter.

19. I am aware that initially there was not a lot of information about Hep C, but anything that was known I believe was not passed on in a timely manner or in a way we could understand.

20. I do not recall being told that Brian was Hep C positive prior to the letter in 1993, if this is indeed as I remember it, I consider it to be a disgrace and very traumatic for anyone to receive such information in such a non-personal way.

21. The only information we received regarding the risks it posed to others was sent to us some time in 1994, and I refer to paragraph 15 above.

Section 3. Other Infections

22. As far as I am aware, Brian did not get any other infections as a result of receiving infected blood products.

Section 4. Consent

23. In the letter, dated October 1993, it stated that blood tests were used to measure how well the liver worked. I have no recollection of Brian being asked in my presence to have blood tests for Hep C or for the liver disease.

24. The records from the NHD show that Brian had blood tests for HIV in April 1985, January 1986 and April 1987. We were never told that Brian would be tested for HIV and I did not know he had been tested for HIV until I received his NHD records.

25. We were not provided with any information nor did we receive any communication from the hospital that Brian would be tested for Hep C. The first time we knew that he tested positive for Hep C was when we received the letter, dated October 1993.

Section 5. Impact of the Infection

26. When Brian was advised by the 1993 letter that he was Hep C positive, we were both devastated and felt numb, it was impossible to comprehend together with the uncertainty surrounding the whole issue of life or death. We were later advised about prognosis and the way in which his health would be affected.

27. After months of soul-searching we decided that we would not burden anyone with Brian's medical condition, this included both of our sons and close family members. We slowly withdrew into our own little world, fending off questions from loved ones that would shed light on the subject. We thought at the time that was the best way of dealing with things, so not to upset others and place

our burden upon them. It also had a negative effect, as we could not share our grief and problems with others.

28. Over time, Brian became a shell of his former self. His physical appearance altered and he looked like a very sick man. We were then forced to avoid people who knew us, as he would always be asked if he was sick. It became more and more difficult and we withdrew deeper into our own little world.

29. The next decision we made was for Brian to give up work, although we were not financially secure we knew as Brian became more unwell, he would be unable to work and if he stayed he would be wasting what precious time he had left. I spent my time fussing and worrying about his every move. However, tried not to let his illness beat him and would go and play golf whenever his body would allow him. Our decision not to tell family and friends did impact on us, as when Brian was feeling unwell we would cancel meals with family and friends and going out.

30. We loved our holidays and travelled all over the world together, but again as Brian's health deteriorated the holidays and thus the enjoyment we got out of them came to a halt.

31. The illness and complications that followed slowly ground Brian down and towards the end, the enjoyment of his life had ebbed away and he was just existing day-to-day.

32. I was told that Brian suffered from cirrhosis of the liver which was followed by liver cancer. The cancer spread to the arteries around the liver, which meant that he could not have a liver transplant.

33. As no treatments were available, Brian was asked and agreed to take part in clinical tests for what we hoped were drugs that may work and help others.

34. Brian was put on Alpha Interferon for 2 months, but this made his health worse and had no positive impact on his condition.

35. He was then placed on Ribavirin, but again this was not successful, although it did work for others. Later on, when his cirrhosis of the liver and his liver cancer was diagnosed, he was told about the option of having a liver transplant, but as stated his condition was too far advanced for this to take place.

36. It took a specialist at Birmingham hospital approximately 30 minutes to tell us that Brian could not have a liver transplant. Brian was so ill, that it took us 2 days to travel to his appointment.

37. A liver transplant may well have been an option if we were told that he had liver problems sooner. We should have at least been given a chance to have a transplant.

38. Brian was always a positive person and we went into the clinical trials full of hope. Our hopes and dreams were shattered and as we did not feel we could share the information with others, we had to shoulder the disappointment ourselves. The drugs which were tested on the clinical trials made him very unwell, when he took them but he continued to take them until the doctors took him off them, as he hoped the drugs would work.

39. Brian's health deteriorated rapidly after he was diagnosed with liver cancer, he went from being a sports fanatic that was out everyday playing golf to someone who struggled to get up and down the stairs on a day-to-day basis.

40. I was totally and utterly devastated when he was diagnosed with Hep C and later liver cancer. I saw my world ending and I did not want to imagine or have a life without my husband. I was not able to tell my family about Brian's illness and often felt the heavy weight of pressure upon me. I cared for my husband in sickness and in health to the best of my ability. What really made me sad was to see him become a shadow of his outgoing and sports-minded self. He had played sports all his life and it gave him great pleasure. For me to see this pleasure taken away from him due to his illness haunts me even to this day.

41. When the illness became too obvious to hide and his body was shutting down, it became clear that Brian was not going to be cured and we had to go

through all of the stress of telling our sons and family members that he did not have long to live, something that to this day, still haunts me. They could not believe it and some of the family members struggled to cope with the news. However, they all rallied around over the final days and weeks. They all came to the funeral and kept in touch after but I was in a very dark place at that time.

42. I believed that life without my husband was pointless. One-by-one I stopped answering phone calls and knocks at the door by our friends. I wanted to be alone. Close family would try to get me out and involved, but I made excuses because I wouldn't enjoy life when Brian's was cut so short. I told the family I was okay and could cope, but deep down this was far from true. It took months if not years for me to come out and face the world. I can never come to terms with my loss fully, but slowly the despair turned to anger... why had my husband died?

43. I began to focus and started to ask questions of the doctors and nurses. I was hit by brick wall after brick wall in trying to get any information. We were told that his records were destroyed and it was no one's fault and nobody knew anything about infected blood products. This helped me, if only a little, to focus myself and helped in the healing process. My grandchildren and great grandchildren will never know their grandad or great-grandad. This saddens me as I believe this could have been prevented. My two sons have questioned our decision that they were not told earlier and regret not spending enough quality time with their dad, but they both respect it even if they do not agree with our decision.

44. I do not believe we came across any stigma with regard to Brian's illnesses.

45. With regards to Brian's education, I do not believe that his Hep C infection had an effect on this. As far as I am aware, Brian did not require further qualifications with regards to his work as a consultant, but his illness was in the early stages and it did not affect him. It was not until the later stages of his illness that Brian's work was affected as previously stated.

46. Being infected with Hep C had an impact on Brian's ability to work and our resulting income. Brian did give up work so he could make the most of the time he had left. He returned to work on a consultant basis but worked fewer hours and on a fixed term contract. This was done to help with the financial situations and once the contract came to an end he gave up work once more as he realised that it was taking too much out of him. Once Brian had fully retired our income was cut by 60% as we lived on his work pension and savings we had put away over the years.

Section 6. Treatment/care/support

47. I believe that Brian was not offered any counselling or support and had this been available to him it might have helped him to cope with his prognosis. I have not been offered any counselling or support and I believe if I was offered the above treatment I would have taken it. I know that my son would have encouraged me to accept the help, because I struggled and became a recluse after Brian's death.

Section 7. Financial Assistance

48. In 2011 I became aware of the Skipton Fund from a relative of Brian who worked for the Haemophilia Society. On the 8th February 2011 I filled in the application form asking the fund for financial support. I was granted a Stage 1 ex gratia payment in the sum of £20,000, which was paid to me on the 1st July 2011.

49. In July 2011 I was told that I may be entitled to an upgraded amount so I filled in the forms, as requested.

50. On the 20th September 2011 I believe a further £50,000 was paid into my account, upgrading the amount to £70,000 in total.

51. On the 4th January 2018, I also received a further payment in the sum of £10,000 from the EIBSS.

52. I have not faced any difficulties with accessing financial assistance with the Skipton Fund; they have always been very helpful.

Section 8. Other Issues

53. When Brian and I travelled, we found that his infection affected our ability to obtain travel insurance. We had to pay a large sum of money for travel insurance. However, we did not let this stop us from going away and enjoying our remaining years together. We travelled abroad until Brian's health prevented him from travelling anymore.

Anonymity, disclosure and redaction

54. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed. GRO-C ....

Dated 11/12/2018