

Witness Name: Jill Hughes

Statement No: WITN5339001

Exhibits: 0

Dated: 16/12/2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JILL HUGHES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23 September 2021.

I, Jill Hughes, will say as follows: -

Section 1. Introduction

1. My name is Jill Hughes. My date of birth is GRO-C 1956. I reside in GRO-C
2. I married my husband ("Glyn Hughes") in 1979, and we have 1 child, Iain Hughes. I am currently retired. Before this, I worked as a secondary school teacher of English and Drama.
3. I intend to speak about my husband's infection with Hepatitis C ("HCV") after he was infected in 1979. In particular, the nature of how I learnt about my husband's infection, how his health had affected him and our family thereafter. Also about how his death had affected our family and the financial assistance I have received. My family and I were aware that my husband was infected

with Hepatitis, however the specific type of hepatitis was not known to us while my husband was alive.

4. My friend was present throughout my witness interview and she has assisted me in providing information.
5. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I do not wish to be anonymous as I would like my story to be known in full.
6. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.
7. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. I have been assisted by my husband's aid memoir in the form of a diary, which he wrote when he was alive. However, these timeframes should be accepted as 'near to' rather than precise dates.
8. I have constructed this statement without access to my husband's medical records, as they were destroyed following his death in 1993.

Section 2. How Affected

9. When my husband was growing up, he was one of 6 siblings GRO-C
GRO-C According to my husband's diary, he received both cryoprecipitate and Factor VIII. To the best of my knowledge, my husband was a mild to moderate haemophiliac suffering with haemophilia A. I believe that he had approximately 12 per cent of his own clotting agent prior to being infected with HCV. At one point, he went through 10 years without any incidences of bleeding.

10. My husband had a relatively active life, his parents were adamant that his disability would not interfere with his life and he attended a local school, Leeds Modern. There was no suggestion that my husband would attend Lord Mayor Treloar College and was expected to live a life as typical as possible. His family were very sporty, particularly rugby. However, He GRO-C were not allowed to play any contact sports due to the risk of injury and excessive bleeding.
11. My husband was generally treated for bleeds at St James' Hospital in Leeds. He received cryoprecipitate as a child and adolescent and from 1967, had received 'Epsicapron' to aid with his bleeds. This came in a granular form and had to be dissolved in water and drunk. He only received cryoprecipitate as needed and in Leeds it was always prepared before he had arrived in hospital.
12. When my husband and I moved to GRO-C in 1979 and had regular visits to hospital the cryoprecipitate only began to be prepared when he had arrived, albeit the hospital had been first notified he was on his way. This led to greater risks for my husband, as any delay to the administration of cryoprecipitate led to greater damage. The bleeding would take longer to be brought under control and the direct effect this had on his joints and muscles took longer to recover from.
13. In early 1977, my husband received Factor VIII during a dental appointment, where he needed to get his teeth extracted at St James' Hospital, Leeds. During this occasion, he had mentioned that his doctor, Dr Swinburn in spite of my husband's haemophilia had been very surprised by the amount of blood he had lost during the night. He had suffered from stomach ache and vomiting along with constant bleeding. The doctors then hypothesised that he had got hepatitis and jaundice as a result.
14. At a later appointment in February 1977, he was diagnosed with 'yellow jaundice' at Seacroft Hospital in Leeds. As a result my husband was given some time off work however he was not told that he suffered from Hepatitis

NANB (known now as Hepatitis C or HCV). It was around this period that he had suspected he had a form of Hepatitis. [GRO-C], [GRO-C] also had frequent yellow eyes, severe stomach pains and some fatigue. It was likely that he too was infected with HCV as a result of his own injections of Factor VIII.

15. My husband had frequent appointments with GP's at Netherfield Health Centre, now known as Trentside Health Centre where his symptoms including jaundice and stomach pains were acknowledged, however no referrals to specialists were made.
16. We were never informed that my husband could take Factor VIII abroad and as a testament to his character, he did not allow his haemophilia to interfere with his day-to-day life. Following his diagnosis with hepatitis, my husband did not have any major bleeding incidents for 10 years. During this time, we frequently travelled and went on holidays abroad.
17. My husband had tested positive for HCV at the time of his death in 1993, however unfortunately all his medical notes had been destroyed. Therefore, many details regarding his death remain unknown.
18. In 1993, my husband had passed away and the cause of death on his death certificate was identified as a cerebral haemorrhage, with the secondary cause of death being haemophilia. It was not acknowledged or known for certain that Hepatitis C had caused the cerebral haemorrhage and in turn, my husband's tragic death.
19. My husband was given no warning regarding any risk of infection of blood products and was not aware of his diagnosis of HCV while he was alive. He was given no advice or warning regarding his recurring jaundice or stomach pains since 1977. The doctors did not inform him he had Hepatitis C or Hepatitis NANB until the time of his death. We naturally did not receive any warning of cross contamination of blood products, for example through sharing of toothbrushes and blood to blood contact in the event of an injury.

20. It really frightens me to acknowledge that his death could have been prevented. I believe that my husband and my family should have been informed about the risk of infection transmitted through blood products. A culture of inadequate service and care was perpetuated throughout our visits to our GP. There was also a culture of not 'bothering' the doctor, we were aware of procedure regarding haemophilia care but not Hepatitis care. We believed that my husband had Hepatitis and was cured. We were not informed that it was HCV nor of the chronic nature of HCV.

Section 3. Other Infections.

21. To the best of my knowledge, I do not believe that my husband had any other infection as a result of receiving factor VIII or other products.

Section 4. Consent

22. As my husband was not adequately warned of the risks of infection when receiving Factor VIII or Cryoprecipitate, I do not believe he had informed consent when receiving these products. However, as far as I know, he was not tested or 'experimented' on without his consent for the purposes of research.

23. During treatment at the Queens Medical Centre (QMC) in Nottingham, I feel my husband did not receive adequate information on how to treat a Hepatitis infected bleed. GRO-C contracted Tuberculosis at age 11 and was constantly being monitored however my husband did not receive a similar level of care.

Section 5. Impact.

24. The symptoms of jaundice, constant pain and bleeding that my husband suffered of which we now know to be exacerbated by HCV continued, however it did not significantly affect my family and the things we did. Stays in hospital were largely down to haemophilia as opposed to Hepatitis, as we

believed that the Hepatitis he had was cured and not chronic. Once Hepatitis had been identified, he had jaundice and stomach pains but his condition had not worsened. His haemophilia was treated along with his general ailments, however his jaundice was not treated.

25. My husband received no specific treatment for HCV and I feel cheated that my husband could have had such treatment and was not offered it. We thought that he had been unlucky or that my husband had a weak artery. We had never considered that he had chronic Hepatitis. The fact that my husband nor the family were not informed that he had HCV was the biggest obstacle in my husband receiving the treatment he needed.
26. My husband did not know he was infected with HCV, therefore it did not have any impact on his medical records or general treatment. It was clear that there was a lack of concise thinking regarding his care. This had also been impacted by our move to GRO-C from Leeds. The treatment my husband received for haemophilia at St James' Hospital in Leeds was much better than at the QMC in Nottingham. I did not realise at the time that there was a lack of 'joined up thinking' with his care. That said, there was no difficulty in acquiring treatment generally speaking.
27. My husband and I believed that once he had been isolated following his initial bout of jaundice, he had been cured of Hepatitis. We did not know he had contracted HCV and that his condition was chronic. As a result, there was no particular physical, mental or emotion impact of having Hepatitis C on my husband's private, family and social life due to our lack of knowledge.
28. We did not experience any stigma as a result of my husband being infected with HCV, as he did not know it was HCV and the stigma was associated more with HIV/AIDS at that time. Generally speaking, we were not people who allowed what other people thought of us to bother us too much.

29. When [GRO-C] also a haemophiliac, had contracted HCV, it was thought for a long time that he could have been infected when he borrowed a £5 note from my husband. From what we now know about transmission, it was more likely that [GRO-C] had contracted HCV from his own Factor VIII injections. There was no warning about cross contamination of blood as we weren't aware that he had HCV so therefore did not know how it could be transmitted.
30. As a result of my husband's illness shortly prior to his death, we were not able to adopt a second child. This was particularly distressing to us all but had a profound effect on our son who was just five at the time.
31. When my husband and I moved to [GRO-C] to look after my parents, my husband had to give up his job working in a car depot. He was able to work sporadically over the years, however due to having haemophilia, he had to be let go from various jobs. This was not due to him having contracted Hepatitis, but rather his haemophilia as disabled people were considered to be a nuisance and faced employment discrimination. This did not affect his reputation and his employers always thought highly of him, giving him glowing recommendations everywhere he went. During a period of time when he had no bleeds for around 10 years, he had a good work record and was thought highly of by his employer.

Section 6. Treatment/Care/Support

32. As my husband was not aware he was infected with HCV, he did not face any obstacles to obtaining care. He was treated for bleeds as and when required, primarily at the QMC in Nottingham after 1979.
33. We were not familiar at the time with any treatment for HCV and he was not offered any treatment such as Interferon or Ribeveron, to the best of my knowledge. There may have been some discussion around these drugs,

however he did not appear to be offered them and there is no reference to them in his diaries.

34. As my husband did not know he had HCV, but knew he had hepatitis, he did not face any major difficulties in obtaining care due to HCV. However, there was one incident when he was isolated in Seacroft Hospital during a bleeding episode. He did not receive any treatment there and was informed he simply needed to rest and be isolated from the rest of the hospital, as it was believed that his Hepatitis was contagious. He wanted to discharge himself, however he was told by a nurse that it was likely that he would bleed to death due to his combination of Hepatitis and Haemophilia. Despite this, he did not receive any treatment for HCV.
35. The consequences of my husband not being offered treatment were severe in ways that one might not think of at the time. Life had never been the same since my husband passed and our son had effectively grown up without knowing his father. They had a very close relationship while he was alive and he has recently uploaded pictures of him and his father together on Facebook for the anniversary of my husband's death. I have never truly been happy since his passing. I am weighted down by the responsibility of having to deal with everything on my own.
36. The impact has been great on my son who has since moved to Canada. He would tell his classmates that his father had been stabbed, as a youngster he could not understand a brain haemorrhage. Our son would have loved to have had a brother and that opportunity was taken away due to his father's death.
37. I have received no counselling at any stage as a result of what had happened. My husband was generally very cheerful while he was alive and no counselling was offered to him while he was alive.

Section 7. Financial Assistance

38. My family was given money from the Skipton Fund after applying in 2011. We received a check of £20,000. I was told that I had almost missed the deadline for applying and had completed my application a day before applications were closed. I was not aware of the Skipton Fund until 2011, which was two decades after my husband had passed away. I have only recently become aware of the 'England Infected Blood Support Scheme'.
39. I was informed of a more regular payment scheme however I was told that I was not eligible for monthly payments. I was given a winter fuel allowance of £540 this year and last year. I was not aware of the fuel allowance until last year and believed that the payment made into my account by the NHS for the allowance was a mistake and likely to have been someone else's wages! I was later informed it was the winter fuel allowance.
40. Prior to my application to the Skipton Fund, there had been no contact from QMC in Nottingham and was not given advice on applying for similar schemes until then. When I was eventually contacted, I was told my application would be unlikely to be successful as there was very little evidence of my husband being infected through Factor VIII as my husband's medical records had been destroyed. However, out of the blue, my application was successful. The process of applying however was relatively straight forward. I was shocked and surprised to receive the funds and it felt completely unexpected. I may have had to sign a consent form when applying for the Skipton Fund, however I am not aware whether or not it preclude me from pursuing litigation against the NHS or the Government.
41. Subsequently I was not offered any further financial assistance. I was told that any other financial assistance available was means tested and I would not be eligible as I was earning at the time. I was very keen to work and always wanted to take responsibility for all I could do. I juggled work

responsibilities with care responsibilities for both my parents and husband and also as a mother.

Section 8. Other Issues.

42. I believe my husband should not have been given infected blood products, certainly if it was known that these blood products were contaminated they should not have been administered to patients. I also believe this Inquiry is long overdue and the matter should have been properly scrutinised long ago.

Statement of Truth

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

Signed GRO-C

Dated 16/12/2021