Witness Name: George Liam Nevin
Statement No: WITN2787001
Exhibits: 0
Dated: June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GEORGE LIAM NEVIN

I, George Liam Nevin will say as follows:-

Section 1. Introduction

1. My name is George Liam Nevin. I was born on GRO-C 1999 and I live at GRO-C GRO-C Merseyside, GRO-C with my parents and brother.

2. My father, Sean Philip Nevin (born on GRO-C 1969) was infected with Hepatitis B and Hepatitis C (genotype 1A) from contaminated blood products.

3. My father has provided his own Witness Statement to the Inquiry (WITN1425001). My mother and brother have also provided Witness Statements to the Inquiry (WITN2786001 and WITN2788001 respectively). My Uncle Andrew was similarly infected with Hepatitis C as a result of treatment with contaminated Factor VIII concentrate and has given a Witness Statement to the Inquiry (WITN2785001).

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

Section 2. How Affected

5. My father has mild haemophilia A. He was treated at the Roald Dahl Centre at the Royal Liverpool Hospital and was highly likely to have been infected with the Hepatitis C Virus (HCV) in 1982 when he was given his first dose of Factor VIII (FVIII) concentrate.

6. I was first told about my father's HCV infection in December 2016, when I was 17 years old. Dad was about to start Harvoni/Ribavirin treatment in an attempt to cure the virus. There was also talk within the household about my father receiving an ex gratia payment from the Skipton Fund. My parents thought it was the right time to tell me and my brother, Harvey.

7. I didn't know much about HCV at first. Harvey and I researched it and were scared by what we learned. The stories and accounts that we have read from others infected and what they too have been through are hard to digest. Our parents did not tell us a lot of the information about my father's liver as I don't think they wanted to scare us. They simply said my father had Hepatitis C and would have treatment in the very near future. Much later when Dad was having his clearing treatment, we had some longer conversations about HCV and it's impact on his life.

8. My parents were told that my father had been infected with HCV in 1994 at one of my father's routine haemophilia appointments. His consultant at that time, Dr Hay, was not present. He was told in a cold and blasé manner by a panel of three health professionals, one whom my father had never met.

9. I consider the time taken and the manner in which my parents were informed of the HCV infection to be poor. My father was never warned of the risk of infections before being given FVIII. He was given unnecessary FVIII treatment in

1982 as part of a training exercise. Without warnings about risk, my grandparents did not provide informed consent to the treatment. My Grandma always blamed herself (as she believed she was doing the best possible for her sons) and my Grandad never spoke of the issue after Dad and Uncle Andrew were infected.

Section 3. Other Infections

10. The doctors only ever informed my father that he had Hepatitis C. Only when my father's medical notes were recently obtained did we, as a family, learn from the notes that my father had also been infected with Hepatitis B, believed to have self-cleared.

11. In or around 2004, our father was notified that he had been exposed to vCJD.

Section 4. Consent

12. I believe my father was treated and tested without knowledge and consent and/or being given adequate or full information.

13. I believe my father was treated for the purposes of research. He was 'trained' to self administer FVIII treatment with three live batches in 1982 by his then Consultant, Dr B A McVerry, less than 40 days after the Oxford Haemophilia Centre sent a letter looking for 'PUP' patients to study infectivity rates. Dr McVerry had been researching transmission and types of hepatitis in the late 1970s/early 1980s.

Section 5. Impact

14. My father has had many HCV associated health issues over the years. Dad would on occasion be taken into hospital and we did not understand or really know what was happening at that time.

15. Some of the physical effects of HCV on Dad have been fatigue, joint pain, arthritis, scarring to the liver (cirrhosis), fatty liver and abdominal pain. There were serious health issues and complications before my brother and I were born where it was believed he may not survive. Approximately 6 years ago, Dad was taken into hospital with severe abdominal pain. Dad has since told us that he thought his condition at that time was terminal and believed he would never see us grow up. The root cause of his pain was never identified.

16. The mental effects are severe irritability (especially during and after his clearing treatment), mental instability, lack of motivation and depression. He has undiagnosed PTSD (intrusive thoughts and dreams), extreme frustration and anger (especially when reminded of events he has forgotten) and lack of concentration. My father was told he could expect to live for approximately 25 years from infection before serious/terminal issues set in. He wasn't told about the infection for the first 12 years. That left him with a life expectancy of 13 years from being told he had HCV. That is a lot to deal with.

17. During Dad's clearing treatment he experienced side effects to including flaking skin, tingling hands, nausea, flu-like symptoms, anaemia (they considered withdrawing the treatment for anaemia), weight gain (104-110 kg) and his skin tone changed to grey. Dad became breathless whilst out walking our dog on a flat road. He would have to take fast and deep breaths and it was alarming to witness. We had been informed that there would be almost no side effects.

18. Prior to the treatment our father was quite relaxed, during the treatment he had intense mood swings which continued after treatment. There was palpable tension in the family household that we felt returning at the end of a school day, wondering if he was going to be in a bad mood. He wasn't happy to be on his own and he wasn't happy when we were around him. I felt that we couldn't win. He was depressed, short tempered, lacked motivation and suffered with insomnia.

19. Our parents took extra precautions when we were younger to avoid any potential infection. We were told never to tough Dad's toothbrush or razors. The stigma that people of our parents' generation associate with HCV is huge, especially back in the late 1980s. Our parents worry about stigma to this day.

20. As my brother and I were protected until recently, the impact of the infection on us in comparison to others has been limited. Our journey has been made up with concern for our father's health, frustrations and dealing with the effects of the clearing treatment on our father. We have tried, even though difficult at times, to remain supportive and have found it important to do so for both our own and our father's mental and physical health.

21. The impact of our father's infection on our mother is huge and is largely covered by her statement. Our parents have struggled financially. They have been under huge financial strain. Given my father's limited life expectancy throughout his working life he has had to balance the need to support us financially to the detriment of his health with his quality of life. My father has been unable to work since being informed his liver is cirrhosed and undergoing HCV clearing treatment. His HCV has always had job suitability/employment issues for him. Our parents are hard working people and it is wrong for them to have had to struggle and rely on our grandparents and their friends to get by. We had no savings and we were living from hand to mouth. The holidays we have had have

been modest ones at home in the UK except the holidays paid for by our godparents. Our godparents also lent us a car for three years because we didn't have one.

Section 6. Treatment/Care/Support

22. We were informed by our parents that the first and only viable treatment on offer to my father was Interferon in or around 2004. He was unable to accept it due to the extreme side effects, work, mortgage and family commitments. Between the time of Dad being infected and treatment, there was a definite lack of action from the doctors. There were no regular appointments in relation to his liver or his virus and he had to instigate receiving treatment. There were no scans offered to him. All blood test results and important letters are missing from Dad's medical notes and records. The treatment had to be approved by NICE despite being available for some period of time and Dad was told to act fast in case funding was withdrawn. We weren't told anything about the side effects and so we didn't know what to expect.

Section 7. Financial Assistance

23. Dad heard about the Skipton Fund after it was announced on the national news regarding it's inception in 2004 and received a one-off £20,000 payment. Dad also instigated contact with the Caxton Foundation but was told he was ineligible for financial assistance because it was means tested.

24. In July 2016 Dad started to receive the new Stage 1 annual payment from the Skipton Fund of £3,500. When the EIBSS was set up he applied for payments under the SCM (Special Category Mechanism) and received £15,655 in 2017/18 and £18,500 in 2018/19.

25. Dad was told that he was entitled to the Stage 2 Skipton Fund payment when the hospital diagnosed a cirrhotic liver in 2016/2017 and was put forward for his clearing treatment. Our parents told me and Harvey that they were expecting the payment as 'an ex gratia capital payment', thinking it would help soften the blow in telling us that Dad was unwell and needed treatment. During this time, he was labelled as having cirrhosis and it has been recorded in his medical notes that he was definitely eligible for the Stage 2 Skipton payment. Dad filled out the application and provided the supporting letter. He was turned down and turned down again on appeal because of lack of 'evidence'.

26. There are no clear parameters for the Stage 2 eligibility. Dad's haematologist and hepatolgist clearly indicated Dad should have the Stage 2. The parameters, indications and levels need publishing. At present you can only take the word of the Skipton Fund on the threshold level for payment. We suspect it became harder to gain Stage 2 status as time went on. We felt the consequence as a family in not receiving what my father is due. Dad had to borrow money from my Grandad and it is so frustrating as it is something that did not need to happen.

Section 8. Other Issues

27. The little bits of news that has come out following the announcement of this Inquiry has helped but there needs to be far more awareness. Over half of the haemophiliacs infected have died. Statistically we are lucky to still have our family intact. Russian roulette was played with my father's life. People are starting to realise that my Dad wasn't just 'unlucky'. There was a systematic failure of thousands of people on the part of the NHS.

Anonymity

28. I do not want to apply for anonymity.

29. I would like to give oral evidence to the Inquiry.

Statement of Truth

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

GRO-C

Signed……………………………………………………

Dated 07/06/19