Witness Name: ALEXANDRA ROBINSON
Statement No: WITN5270001
Exhibits: 0
Dated: December 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ALEXANDRA ROBINSON

I, Alexandra Robinson, will say as follows:-

Section 1. Introduction

1. My name is Alexandra Robinson. I was born on GRO-C 1983 and I live at GRO-C GRO-C County Durham GRO-C

2. My father, Charles Bellingham (born on GRO-C 1961), was infected with the Hepatitis C Virus (HCV) through contaminated blood products. He died after having a gastrointestinal haemorrhage on GRO-C 2006, aged 44.

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

Section 2. How Affected

4. My father had mild Haemophilia A. He was treated at the Haemophilia Centre at the Glasgow Royal Infirmary with Cryoprecipitate initially and then Factor VIII (FVIII) concentrate.

5. My father was informed that he was infected with HCV sometime in the late 1980s/early 1990s. I do not know exactly when, as my brother and I were just children at that time. My father later relayed to us (on several occasions) the way in which he was told that he was infected. He said that he was called into a room at the Haemophilia Centre with 12-15 other people. They were each given an envelope notifying them that they had all (without exception) been infected with HCV. My father was one of just two people not to also be co-infected with HIV. The manner in which my father was given this news affected him in a big way. He was shocked by it. He said it was awful. He told me that he was handed a 'death sentence' that day. He was left devoid of any hope.

6. I do not know what information or advice my father was initially given to help him understand and manage the infection. I remember that my father was quite accident prone and didn't want us (my brother and I) anywhere near him if he had an accident and was bleeding. Being a child, I was curious and wanted to take a look at what had happened, but I remember my father being terrified and telling me not to come near him. In retrospect, our parents were clearly worried about the risk to us.

7. My father was very upset by how he was infected. He always said that he had been treated as a guinea pig. He had no trust of doctors.

Section 3. Other Infections

8. My father was later notified that he might also have been exposed to vCJD. I remember him referring to it as 'Mad Cow Disease' and trying to shrug it off with 'Oh God another thing, what else?'

Section 4. Consent.

9. My father believed that he was used for the purposes of research. He always said that he was treated as a guinea pig. He was in shock to learn that he had been tested for HIV and HCV when he was informed, as part of a group, that he was infected with HCV.

Section 5. Impact

10. My father (Dad) had a multitude of health issues to contend with. He was unable to work after an accident he had whilst working as a lorry driver. Before that, having HCV had already taken a toll on him and his health was in decline. Around the same time, he had his first attempt at clearing HCV and the side effects were terrible. Other dads I knew worked, but he wasn't physically able. Mentally, he felt robbed of being able to work. He had always been a provider for his family. My Dad would say 'I'm medically retired', but he was upset about it. He was a real grafter. He tried to find work and would have worked any job he could find. Dad felt ashamed that he had HCV and ensured that it was not made common knowledge. People didn't want to employ him. It was thought of as a dirty infection. He didn't generally talk about money except in relation to the lack of it. My Dad worried about the stigma associated with having HCV and we also suffered financially because of it.

11. My mother, father and I moved from GRO-C in Scotland to England when I was 16 years old (in or around 1999). My older brother was supposed to follow us down, but that never happened. My father's haemophilia care transferred to Dr Talks at the Victoria Royal Infirmary in Newcastle.

12. Before our move, Dad had Interferon and Ribavirin treatment over what was meant to be a long period of time (six months or more). The side effects were horrific, and he couldn't complete it. He was completely wiped out and his mood swings and temper outbursts were awful. He had no trust in his doctors to keep him on track and no belief in what he was taking. He did not again attempt clearing treatment until relatively shortly before his death. He only gave it another try because he so very badly wanted to get better and we talked him into it.

13. My mother (Mum) was also very unwell with MS. We moved to England in the hope of additional support from my mother's family. She died 18 months before my father. I had a lot to contend with at a young age. My Dad was in and out of Freemans Hospital in Newcastle and found it hard to look after my Mum. She had looked after him since their marriage. At times they were both in different hospitals. They each leaned on me for emotional and psychological support as well as practical help. It was down to me to speak to hospital consultants and oversee their medication.

14. My Dad developed liver cirrhosis. He regularly had hospital appointments and hospital stays. He spent months and months in hospital in the last four years of his life. He had tubes draining fluid from his stomach through ascites. He was in constant, excruciating pain. I remember him wanting to pull everything out and come home.

15. Dad had internal bleeding and would violently vomit blood. He had to have operations to tie his gullet. I have blocked a lot of my memory of what Dad went through at that time from my mind as a coping mechanism. His stomach was bloated. He was sick whatever he ate. He was skinny. He looked grey and drawn and ill. To anyone that didn't know him, he looked like a 'down and out'. He was no longer the man he used to be. He had no motivation and he looked unkempt. He suffered with horrific depression and was on medication for his mental health. It was all a constant battle for him. He was covered in sores and didn't like to be seen. The only thing that kept Dad going was to ensure Mum was OK and that she had the care she needed.

16. Ironically, Dad had his first HCV negative test result (following his second attempt at clearing the virus) just before his death and probably looked the best he had done for many years. He could walk (aided with a stick). He had tried to make some small changes to his routine to try to motivate himself. He was even able to go to Portugal for a first holiday in decades, before a second test due to check that the virus had remained undetectable. He died after several weeks in intensive care in Portugal with liver complications having suffered a gastrointestinal haemorrhage.

17. In losing his life at the age of 44, my Dad had an even shorter life than he was given to reasonably expect when he was first informed that he had been infected with HCV through contaminated blood treatment. Having mild haemophilia, in itself, is not a death sentence and this tragedy could have been prevented. Dad never had the chance to see and get to know his four grandchildren. My brother and I have two each. He wasn't there to see us marry and to walk me down the aisle. My brother has been deeply impacted and now has a deep-seated fear of death.

Section 6. Treatment/Care/Support

18. No-one in the family was ever offered any psychological support.

Section 7. Financial Assistance

19. Dad took a pay out from the Skipton Fund not long before he passed away as there was still some of it left in his account. Dad had to take the funds through fear that he had no other choice. He was told they all had to agree and if one person said 'no', there would be no pay out to anyone. He was pressurised as a 'take it or leave it' one time only offer. My Dad's financial circumstances at the time meant he couldn't say 'no' to it. He was hoping to buy my Mum a specialised bed as she was as bed bound with MS. She died before he received the funds, and this deeply upset Dad as he felt he failed to be able to provide her with the equipment she needed.

Anonymity, disclosure and redaction

20. I do not wish to apply for anonymity and I am aware that this statement will be published and disclosed as a part of the Inquiry.

Statement of Truth

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

Signed.. GRO-C ....

Dated......3-02-2021........