

Witness Name: Simon Donnelly

Statement No.: **WITN2125001**

Exhibits: **WITN2125002-003**

Dated: 3rd December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SIMON DONNELLY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5TH November 2018.

I, Simon Donnelly, will say as follows: -

Section 1. Introduction

1. My name is Simon Donnelly. My date of birth is the GRO-C 1964. My address is known to the Inquiry. I am a Chartered Accountant, in full time employment. I intend to speak about my father Tom Donnelly's infection with hepatitis C. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him, our family and our lives together up until the point of his death on the 28th February 2015.

Section 2. How Affected

2. My Dad was born on **GRO-C** 1935. He died of a stroke in 2015. Dad was diagnosed with haemophilia A. His condition was considered at times to be mild at times to be moderate. I exhibit a letter from my late father's medical records dated 16 April 198k as **WITN2125002** and a letter dated 23 June 1983 as **WITN2125003**. My memory is that he attended hospital regularly for bleeds but I couldn't put a figure on how often he attended hospital.
3. I don't know the name of the products that Dad received, I remember hearing Factor VIII being mentioned but I couldn't say for sure. The impression of the treatment history of my father which we have as a family is narrated in the statement of my sister, Roisin Donnelly.
4. Dad was treated at the Haemophilia Unit at the Royal Infirmary Glasgow. Interestingly when I was doing consultancy work I had to do some work at the Unit and the people there could recall Dad and told me about what a wonderful man he was. I don't think there were other hospitals involved in his care that I am aware of. I don't know the names of the doctors that prescribed the products to Dad.
5. I don't know the dates he was infected. It could have been at any time, 60s 70s 80s I don't know. My mother, Catherine Joyce Donnelly has been working hard to obtain his medical records. It is not clear from them when he was infected. It does not appear that that is information which was ever shared with him.
6. Mum and I have discussed this and I don't believe Dad was advised of any risk of being exposed to anything at all in the products which were used to treat his haemophilia.
7. I believe Dad was tested at some point in the 1980s for HIV because at that point there was an awareness that haemophiliacs were being

diagnosed and dying of HIV. Dad was tested and this came back saying he was HIV negative. Shortly after that, I do not know the exact date, he was further tested and it was discovered that he had hepatitis non A non B, later described as hepatitis C. I believe from his records that he was told of his diagnosis in 1994. The records suggest that he may well have been tested before that, perhaps in 1992.

8. I can't answer if the information was adequate about what it would mean for him to be infected. It's not the kind of thing he would have shared with me. I doubt it.
9. Mum will be able to answer this question, properly as I don't know if there was information about the hepatitis C which should have come to him earlier.
10. I don't have views about how the results were communicated. Mum will have a view on this. Dad was a private person he wouldn't have shared this information with me.
11. I don't know what information Dad was given about the risks of spreading infection.

Section 3. Other Infections

12. I have been told that he was told that he was liable to have been exposed to Variant CJD. I don't know how he was told about this or how this made him feel, we did not discuss this. His medical records do suggest that he was sent a good deal of information about being at risk in around 2004.

Section 4. Consent

13. It is possible that my father was tested without his knowledge, given information I have seen in the media, I don't know the answer to this.

14. Again, I would doubt he would do anything without giving his consent but I don't know. The real issue is whether he was given enough advice to consent properly.
15. It is possible that my father was tested without being given full or adequate information. My mum may be able to provide more information on this.
16. My father could have been tested for the purposes of research, given things I have read in the public domain about what has happened, the medical records are missing, my mum may be able to provide more information.

Section 5. Impact

17. Dad had a lot of fatigue. He didn't do anything. He gave up work as a lecturer early and I know that he suffered from acute depression. He was always in pain, he kept to himself but he certainly gave off sounds that indicated he was in pain.
18. I am not sure what came from the hepatitis C infection. All I know is that he was never well. He was never a well man, he got to the stage that he rarely left the house.
19. Dad died in February 2015. He wasn't well and deteriorated over the last 5 or 6 years of his life, particularly his movement. It is difficult to put in medical terms; his health was to the point that he never did anything. He died when my son, [GRO-C] was very young. I remember that sometimes he would see [GRO-C], but other times he would say to my mum "*Don't bring him to the house*" because he wasn't up to seeing [GRO-C]. Throughout my childhood he never did much with us. I don't know the timescales of when he gave up work, but I do know that he gave up work way in advance of what would be considered a

normal retirement age, even for a lecturer. He just couldn't do it anymore.

20. Dad was offered Interferon and he asked the people at the haemophilia unit what it was like. What they said was that he would definitely feel worse and there was no guarantee that it would make him better. His response to this was that given that he couldn't imagine feeling any worse he didn't want to try that. I believe this was in the 1990s. After this, it was just a case of managing his pain and going to the Unit whenever he needed to go to the Unit. Dad's death certificate says that he passed away from a "cerebral bleed, haemophilia".
21. I am not aware of any obstacles to treatment.
22. I don't know, I can't answer if there were other treatments that were not made available to Dad.
23. Dad never underwent treatment so this question does not apply.
24. I'm not sure how it impacted. One of his real pain areas was around his teeth and gums. But how that impacted things I don't know. I am unsure how often he saw the dentist. I just know he always had pain there and bleeds there.
25. He didn't leave the house much and wasn't keen on people coming into the house. From what I can gather, before I was around, he was a very sociable person and through this he became the total opposite. I have an older sister, Roisin, who has 3 girls. They are considerably older than GRO-C. When they were the same age as GRO-C maybe around age 7, they would come up from England to visit, he would say "*Does she have to bring the girls with her?*".
26. I don't think there was much stigma around his infection as it wasn't something that we really talked about. My close friends knew that he

wasn't well, but they didn't know what it was. It wasn't something we discussed.

27. There were no educational effects that apply to this.
28. Dad was a lecturer of English at a further education college. He did this all his days, until he could not cope with the work any more. He went to Glasgow University and did English. I think he may have then been a teacher and went onto being a lecturer. He stopped work, in the 80s or 90s. I don't know if it was early retirement or if he just stopped working, all I can recall is that he wasn't working anymore. We were never on the breadline, we were never a family buying Bentleys, we were ok. My mum was a teacher so she always worked, we were always ok. Dad never discussed how he felt about giving up work, he would never have that conversation with me.
29. I was a child going through this period, but I don't think it ever had an impact upon my own schooling. We never did much together anyway, not that I can remember. I was never in fear of telling teachers anything or anything like that. There hasn't been an impact on my working life, I don't discuss it with colleagues or even friends really.

Section 6. Treatment/Care/Support

30. I have never been offered counselling in my life and I don't know if Dad was offered counselling. My Mum will be able to answer this. I believe he did develop the depression as a result of the infection and giving up work etc. In my mind I can remember the symptoms of depression starting to appear around the time he was diagnosed with hepatitis C. I don't know if it would have helped him, or if he would have done counselling.

Section 7. Financial Assistance

31. I am unaware of the details of this, so I did ask my Mum about this. What she told me was that there is something called the Skipton Fund. My Dad's attitude was that he was not going to apply for anything as his opinion was that it was the Government and the NHS that had done this to him so why should he go and ask. Eventually he was persuaded by the Haemophilia Unit that he should apply to the Skipton Fund and he received £20,000 and that is all that they ever got, as far as I am aware.
32. I don't know what is involved in applying for assistance.
33. I think the main obstacle was Dad himself. When I asked Mum about this, she said that one of the other obstacles was that she said there was several funds, one of them was means tested so they didn't even look at that fund.
34. I don't know about any preconditions for the grant of financial assistance.
35. A one off payment of £20,000 that you have to ask for is just appalling given what happened.

Section 8. Other Issues

36. My mother Catherine Joyce Donnelly may have more comments about any other campaigning that she has been involved in, otherwise I have no further comments.

Statement of Truth

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

Signed

GRO-C

Dated

29. 4. 19