Witness Name: Paul James Alan Fitzsimmons
Statement No: WITN1219001
Exhibits: 0
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PAUL JAMES ALAN FITZSIMMONS

I, Paul James Alan Fitzsimmons, will say as follows:-

Section 1. Introduction

1. My name is Paul James Alan Fitzsimmons. I was born on GRO-C 1978 and I live at GRO-C Cheshire, GRO-C. I have been married for 8 years to my wife, Laura, and we have 2 children together, GRO-C and GRO-C who are 6 and 4 years old respectively.

2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Infected

3. About the age of two years' old, I had a bad facial injury following a fall which resulted in prolonged bleeding from my teeth and mouth. I was tested for clotting deficiency and was found to have a Factor IX (FIX) level of about 20% and diagnosed with Haemophilia B.

4. I do not know what blood products I received but I believe I was given contaminated FIX between 1982 and 1989. As a result, I was infected with Hepatitis C (Hep C).

5. I was treated at the Haemophilia Centre in Manchester.

6. At the time, information was not provided to my parents. My mother was a sister in an Intensive Care Ward in Manchester/ Salford, but despite being a healthcare professional, she was not given any information about the known or unknown risks associated with FIX.

7. My parents told me about my diagnosis just after my 17th birthday in 1995. They had found out, purely by chance, several weeks previously when a doctor casually enquired if my parents knew that I had Hep C. Other than the information that my mother gave me, I was not provided with any information by healthcare professionals. By this point, my clotting factor had normalised (I was later diagnosed as probably having Haemophilia B Leyden) so I was having much less contact with the Haemophilia Centre in Manchester.

8. I was not given adequate information to help me understand and manage the infection. I do not recall any doctor or healthcare professional talking to me about the Hep C until I began a course of treatment shortly after being told that I had it. Because of this absence of information, at a point where a young adult is just coming to terms with the virus, I contributed to the Haemophilia Society's pamphlets that were produced for young people with Haemophilia and Hep C so that others wouldn't feel as lost as I did. The publications were called 'Living Life to the Full' and 'Alive and Kicking' and were published in 1999, about 4 years after I was informed that I had contracted Hep C.

9. I believe that information should have been provided to me earlier. I was over the age of 16 and was bright and intelligent and could have easily comprehended the scale and magnitude of the news. I could have used that information to better manage my response.

10. I believe that the way my test results were communicated to me was terrible. I understand that I had been tested for Hep C much earlier (several years earlier) but my parents and I hadn't been informed that I had Hep C until 1995.

11. I was given very minimal information about the risks of others being infected through me as a result of the infection. I was told to avoid unprotected intercourse but that is about as far as it went.

Section 3. Other Infections

12. I did not have any other infections.

Section 4. Consent

13. I believe that I was treated with blood products that 'others' knew were likely to be contaminated and I was tested without mine (or my parents') full knowledge, consent and without any information. I was a mild haemophiliac and I believe I was the ideal candidate for testing new treatments on.

Section 5. Impact of the Infection

14. The mental effects of having Hep C were perhaps more painful for my family than they were for me. I was a very positive teenager and I was able to handle the news pretty well and I felt enormously fortuitous not to have contracted HIV as well through contaminated blood products. My sister, who was two years' younger than I, took the news pretty hard and was upset for a long period of time. We were always very close and seeing the impact on my sister hurt me a great deal. My mother was strong, and as a senior nurse, could understand the practical implications of the virus and was much more useful to me than any doctor or healthcare worker. My father couldn't really talk about it much. Both my parents were heartbroken about my condition and it undoubtedly created stress.

15. I received three 6-month courses of Interferon between 1995 and 2001, but as the treatment was unsuccessful, it was felt that I shouldn't have more – despite knowledge within the community that Interferon would help minimise the risk of

cirrhosis, especially as I responded well to the drug during treatment (during treatment I would quickly become PCR negative). I had a successful 12-month course of Pegylated Interferon and Ribavirin in my late 20s. I received the 'all clear' just before my 30th birthday.

16. When I started to become aware of the success in fighting Hep C by combining Interferon with Ribavirin, I asked the Hepatology specialist at the Royal Infirmary of Edinburgh (RIE) (where I was an out-patient between 2004 and 2014) if I could access the treatment. I was told at two out-patient appointments that I couldn't have the treatment as it was being prioritised for patients with more acute symptoms of Hep C. On one occasion, incensed I couldn't get the treatment I so badly wanted, I asked if these patients were "intravenous drug users". The Hepatologist, accompanied by a medical student said "yes" and I got very upset. I then went to see my Haemophilia consultant (my clotting factor had long-since normalised and I only saw the Haemophilia team as an occasional out-patient) and expressed my dismay. I was delighted when I then heard that my Haemophilia specialist had exerted significant pressure on her colleagues in the Hepatology department and that the pressure meant I was soon to receive the treatment. I estimate that I began this final course of treatment in 2006.

17. The physical effects of Interferon alone as well as of Pegylated Interferon and Ribavirin are well-documented and I was no exception. I suffered badly from post-injection 'flu-like' symptoms and these most certainly had an effect on my A-level results. In my last course of treatment I suffered from bad hair loss, significant weight loss and poor eyesight.

18. As a 17-year-old I was refused dental care by my family dentist and I only felt confident going to see a dentist some 12 years' later, when the Hep C was eventually treated.

19. The Hep C impacted on my private, family and social life. As a 17-year-old, at a time when my friends were starting to socialise in bars and nightclubs, I was having Interferon treatment three times a week. This carried on through my university years and into my early 20s. Even still, my alcohol intake was clearly

much less than your 'average student' in the mid-late 1990s and this often alienated me. I knew I had a potentially life-limiting condition; I occasionally smoked cannabis and started smoking cigarettes regularly as the need to escape the virus, combined with a *"what's the point?"* attitude that occasionally overtook me.

20. Whilst usually maintaining a very positive external outlook, I would often find myself furious at the injustice of Hep C. I started to become aware that my blood products had most likely become contaminated with Hep C from the American prison system. All the way through my late teens and 20s, I would occasionally have emotional breakdowns about why it was happening to me and I prayed for my blood to be normal. I wanted a family of my own and I was terrified of the passing the infection on to girlfriends. I was always very open about the virus with partners and had full and frank discussions with them about the need to always use contraception. As I got older, I was able to articulate this more eloquently and as relationships matured, I was able to talk to my girlfriends' parents about the virus as they clearly had their own concerns that needed to be overcome. This wasn't easy, but I felt that being open about my condition ultimately helped tackle some of the ignorance about Hep C.

21. I was acutely aware of the stigma around Hep C and HIV. As my teenage friends at school started to hear of links between haemophilia and HIV/Hep C they started asking me questions. They all knew I was a haemophiliac. To most, I simply denied having either condition- the first friend I told, one lunch-break, threw me out of his car. I only told the academic and support staff. My school, St Bede's College in Manchester, were amazingly supportive and I'll always be incredibly thankful for the support they gave whilst I was getting to grips with the virus, the treatment and my A-levels. It became much easier for me to talk to people about the Hep C when I started The University of Nottingham, as an 18-year-old in 1996. Indeed, I would often let some of the first-year Medical Science students inject me with Interferon (taking the appropriate precautions, naturally). My university friends didn't know me before I was infected, so it was much easier to form genuine friendships with this inquisitive group of tolerant individuals and life-long friends were made.

22. I have suffered educational effects as a result of the Hep C. I believe coming to terms with the condition and the first round of treatment significantly affected my performance in my A-levels. I suffered from bad headaches and 'aching bones' in class the day after the Interferon injection. I was predicted to achieve A/A/B at A-level and I achieved A/C/C. This impacted on my choice of university.

23. In 1997, as a first-year university student, I applied to be a Special Constable in Nottinghamshire Constabulary. I wanted so desperately to follow my father and uncle into the Police Service when I eventually graduated. I declared my condition on my application form (apparently this was initially overlooked), and I passed my exams and practical tests with record marks. The day before I was due to start my training I was phoned at home and told of the oversight and that I wouldn't be able to join the Police force because of the Hep C and the risk of contaminating members of the public or colleagues. I was absolutely devastated. I cannot describe that feeling and it's incredibly painful to recall.

24. The support of my friends and family was invaluable and I left university in 1999 and started working on a graduate scheme in London in 2000. By 2001 I was running train stations in Central London and would quite often find myself in physical confrontations with homeless people, intravenous drug users and various other people who were perhaps more likely to be carrying Hep C or another variant of Hepatitis. By this point I became very much aware of the risks of contracting Hepatitis A or Hepatitis B as well and I would often find myself withdrawing from certain situations where physical confrontation was likely. I was also concerned that I didn't want to pass Hep C on to anyone else. I felt like I was letting my team down and I quit a very promising career in the railway industry and moved in to aviation. Fortunately, I adapted to my new industry very well and I learned to draw strength from my condition and recognise that life could be a whole lot worse, especially for haemophiliacs whose clotting deficiency was much more severe than my own and who had also been infected with HIV.

25. I fulfilled my life-long ambition of becoming a Police Officer, albeit as a Special Constable as my career in aviation was progressing well. I served for four years in Lothian & Borders Police and used my experience to educate my colleagues on Hep C and sensible precautions to employ when dealing with people from groups with a high likelihood of carrying Hep C and similar blood-borne viruses.

26. I suffered some financial effects as a result of the infection. I didn't get a mortgage as a 21-year-old living in London because my bank manager at HSBC told me I'd never get approval.

27. As previously stated, my parents were heavily impacted as a result of what happened to me. It's worth adding my parents bore incredible guilt, although they never admitted it to me. To this day, it's too painful to ask them how they felt.

Section 6. Treatment/care/support

28. I was never offered any form of counselling to my knowledge. Through the Haemophilia Society I volunteered as a 'mentor' to a young adult who had struggled to get to grips with his condition. He sadly died about a year after our last conversation.

Section 7. Financial Assistance

29. I received a Stage 1 payment in the sum of £20,000 from the Skipton Fund in or about 2006. I became aware of this fund through the Haemophilia Society's newsletters. I don't recall any difficulties applying for this 'ex gratia' payment.

30. I have never asked for any other financial assistance.

31. I now receive the annual sum of £4,000 (plus winter fuel) from the EIBSS.

32. I believe I was incredibly fortunate to survive the infection. A £20,000 payment for 25 years of infection and the emotional challenges I faced is simply not good enough.

Section 8. Other Issues

33. To this day, I am deeply affected by stories of suffering and loss from within the haemophilia community and I am determined to live the best life I can to honour the memory of those who've sadly died.

Anonymity, disclosure and redaction

34. I do not wish to remain anonymous.

35. I am willing to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.. **GRO-C**

Dated 12 - June - 19