

Witness Name: Ivan George Mackay

Statement No.: **WITN0374/001**

Exhibits: None

Dated: 18-01-2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF IVAN GEORGE MACKAY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29 November 2018.

I, Ivan George Mackay, will say as follows: -

Section 1. Introduction

1. My name is Ivan George Mackay. My date of birth and address are known to the Inquiry. I am married and I have not been able to work since 2011. My last occupation was as a Senior Project Manager at my own construction company, with a background in carpentry. In December 2011, I married my wife, Christine Mackay and have two children from my previous marriage that ended in 2005.
2. I intend to speak about my infection with the Hepatitis C virus ("HCV"), which I contracted as a result of having been given several blood transfusions during my childhood when I suffered from Rheumatic Fever.

3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the impact it has had on my life and the rest of my family.
4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my witness statement. My wife Christine also assists me, as sometimes my memory is not very good with names and dates.

Section 2. How Infected

5. In 1965, when I was 9 years old, after suffering from severe headaches, fatigue and being unable to walk, I was hospitalised at Cambridge Military Hospital in Aldershot, Hampshire.
6. Although doctors initially thought I had kidney problems, I was soon diagnosed with Rheumatic Fever. I spent 9 months in hospital being treated.
7. Due to my father being a warrant officer in the military, my family had access to military's medical facilities, and I was treated whilst living in a convalescent home run by the Cambridge Military Hospital.
8. During my time in hospital, I suffered from intense nosebleeds where I would lose in excess of two pints of blood. Because of these episodes the doctors made several blood transfusions. I received on average 3-4 blood transfusions a week during my treatment for rheumatic fever, but I am unaware exactly how much blood I was given. It was the only time in my life that I received blood transfusions.
9. Being a minor at the time of treatment also meant that I did not receive any information on my treatment. My mother would act on my behalf following

the advice of the military doctors without hesitation, as noncompliance by her would be recorded on my father's military record.

10. After recovering from rheumatic fever, being discharged from hospital and convalescent home after 9 months of treatment, my life went back to normal, albeit with some heart problems. I was given medicine for this issue and I was told not to compete in sports and to avoid straining my heart. I also returned to school.
11. In 1975, when I was 19 years old, I began donating blood. In 1998, aged 42, I received a call from my local blood donation centre to visit my doctor, but they did not tell me why. When I visited my family doctor in GRO-C, Surrey, he informed that I had Hepatitis, but he did not tell me which strain of the virus I had.
12. I was shocked: I immediately associated Hepatitis with HIV/AIDS, and I thought that I had contracted a sexually transmitted disease. However, the GP, who knew that I often used to go scuba diving, assured me that this was not the case and that I most likely contracted Hepatitis by diving in contaminated water.
13. The GP also assured me that I should have not worried about having Hepatitis because thanks to blood regeneration, I would have been fine in 3 months. I was not offered any treatment and I did not receive any information on the risk of infecting others. I was not referred for any further medical examinations.
14. In 2005, the construction business that I owned went insolvent. This was partially because at that time I suffered from brain fog, confusion and poor concentration and therefore I found it difficult to work.
15. I went to the GP to talk about my symptoms and he referred me to a psychiatrist. The specialist concluded that what I had was due to stress at work, and prescribed me mood pills, Citalopram, which I am still taking

today. It was around this period that my marriage broke down: I have been in a bad mental state for several years.

16. In 2010, I decided that I needed a kick-start, and I enrolled in the *Queen Elizabeth Training College for the Disabled* in Leatherhead, Surrey, to retrain in Computer Aided Design (CAD) software. This is where I met my current wife, Christine, who worked at the College as a welfare officer.
17. Despite succeeding in college, I continued to suffer from ill, stomachaches, fatigue, a feeling of constant weakness and I was also unable to walk. So, in early 2011 the GP referred me to Epsom Hospital. At this point I was already in a relationship with my wife and in the process of moving from GRO-C to Devon.
18. It was only at this point, around Feb/March 2011, that the doctors at Epsom Hospital told me that I had both Hepatitis C ("HCV") and Hepatitis B ("HBV").

Section 3. Other Infections

19. Although the doctors never offered to test me for HIV, I do not believe that I have been infected with any other infection as a result of being given infected blood via transfusion.

Section 4. Consent

20. I was a minor when I received blood transfusions to treat my rheumatic fever, meaning that I was too young to give consent and to be informed on the nature of my illness and treatment.
21. As previously stated, my father was a warrant officer in the military, and my mother would listen to the advice of the doctors at the Cambridge Military Hospital, as not doing so would be recorded on my father's military record.

22. However, I vividly remember that when being treated for rheumatic fever, doctors from all around the world often monitored my heart during physiotherapy. This was because rheumatic fever was a relatively new illness that attracted a lot of medical attention. So yes, I guess my treatment could have been used for the purposes of research.
23. In general, since I became an adult, I have found out that I do not get told about medical tests or treatments for HCV or my liver problems, unless I specifically ask.
24. This does not apply to King's College Hospital where I was hospitalised for my liver transplant, as the medical staff there were up front with me; elsewhere, I was not always provided with full or adequate information regarding my medical tests, treatments or results.

Section 5. Impact

25. When the doctors at Epsom Hospital diagnosed HCV, they were aware that I had already sold my house and that I was soon moving to Devon. So they referred me to Barnstable Hospital in North Devon.
26. In August 2011 after I moved to Devon, I began a treatment for HCV at Barnstable Hospital, which involved tablets, twice-daily self-injections into the stomach and weekly blood tests. Because of my treatment, I have not been able to accept an offer to work as a maintenance manager at a college for the disabled.
27. In Autumn 2011, I got a phone call from the consultant who informed me that I must see him immediately on an emergency appointment and that I needed to have an MRI scan completed. Because we were talking over the phone he did not tell me why and he didn't give any further explanation.

28. Two weeks later, he informed me that due to the HCV infection causing cirrhosis on my liver, I had developed two large cancerous tumours on my liver. He immediately recommended having a liver transplant at Derriford Hospital, Plymouth.
29. Unfortunately the tumours were too large to be viable for a transplant. To be able to have a transplant the specialist explained to me that I had to first reduce the size of the tumour and to cure Hepatitis C.
30. The specialist told me that in order to shrink the tumours I needed to do chemotherapy. So, I ceased all treatments to cure HCV to deal with the cancer treatment. I received 4 rounds of chemotherapy at Derriford Hospital, Plymouth: every time I was hospitalised for 3 days, a catheter was placed into my groin and an injection was made directly into my liver.
31. In January 2012, I was sent to King's College Hospital in London for a full week of tests to assess whether the tumour had shrunk and whether I was viable to be placed on the transplant list. The assessment indicated that the tumours had indeed shrunk and some time between January and June 2012 I was added to the transplant list.
32. I was advised that whilst on the transplant list, it was preferable that the HCV infection be cured before the transplant, and so in June 2012 I resumed HCV treatment at Derriford Hospital. My treatment this time only involved taking tablets and not injections.
33. The treatment gave me many side effects including throat bleeding, on some occasions. I was also fainting and vomiting blood, and I had to have a camera placed down my throat to identify varices.
34. I finished the treatment some time in early 2013 and the test said that I was eventually cleared of HCV. My liver problems still continued as I was waiting for a liver to become available for a transplant. Both during and

after the treatment, I was transported something like 16 times back and forth from my residence in Devon to King's College Hospital, London, by ambulance, only to be told on almost every occasion that a liver was not available anymore due to different problems with the new organ.

35. The trip from my residence in Devon to King's College Hospital is 4 hours, so every time the journey was endless; and on a few occasions I waited up to 3 hours at the hospital before being transported back home.
36. Because of the tablets I was on, I had also started to gain weight. I have been unable to lose weight despite repeated diets: I am currently seeing a lipid therapist to control my weight gain.
37. Because of this issue, on one occasion, I was not given a two-part liver due to my weight. This prompted the professor at King's College Hospital to invite my wife and I to stay in the family rooms at the hospital until a liver was available. In October 2013, I finally underwent a liver transplant, which was successful, albeit with some complications involving cysts developing on my new liver. They gave me a large quantity of morphine and drugs, including anti-rejection tablets, to the point that on one occasion I was unable to recognise my own wife.
38. Although I received a transplant, I still suffer today. I still monitor my liver regularly and my life has changed immeasurably since my transplant. Due to a combination of HCV infection and my liver problems, I suffer from bowel problems.
39. All the medical problems relating to my liver, including cirrhosis, the cancerous tumours and subsequent need for a transplant, were directly caused by my initial infection of HCV.
40. I have suffered various mental and physical effects as a result of being infected with HCV. I often felt tired, weak and fatigued, and I still suffer from poor memory and brain fog. This is where I become lightheaded and

forget where I am and what I am doing. I also often feel confused and my concentration is very poor.

41. My wife helps me with all my medical problems and struggles, and I believe that marriage with Christine saved my life.
42. In regard to the treatment that should have been made available to me, the only thing that I can say is that all of this could have been avoided had I received treatment for HCV infection when my GP initially diagnosed me in 1998.
43. Instead, I was not cleared of HCV until 2013; 15 years later after the GP firstly diagnosed me with Hepatitis. At this point, HCV had caused liver cancer and I was on the transplant list.
44. With regard to the impact HCV had on my education, I have always been a high achiever academically. I performed strongly when passing my 11 plus and I was ahead in the curriculum compared to my peers, due to private tuition at the convalescent home during childhood.
45. I suffered from fatigue and struggled to walk when studying a CAD software course at the *Queen Elizabeth Training College for the Disabled* in 2010. These were all symptoms of Hepatitis C, but I still performed well.
46. However, HCV infection has had a profound impact on my private, family and social life, and the stigma attached to the infection gave me a dirty feeling of being infected, with the sexual aspect of the stigma particularly haunting me.
47. Although my struggles with HCV were not a massive factor with my first wife, one of the reasons why we eventually separated was down to the symptoms I suffered as a result of the infection.

48. The infection has also stopped me from being able to travel; this is particularly difficult considering that my son Callum lives abroad and my daughter Morgan does not live close to me. Unfortunately I have been unable to visit my grandchildren living in South Africa.
49. The infection profoundly impacted my financial situation. The symptoms of fatigue, brain fog and poor concentration, contributed to my construction business (where I was a Senior Project Manager) going insolvent in 2005. It was a job that provided me with a steady income of roughly £50,000 per year.
50. As mentioned above, the HCV treatment and the treatment for liver cancer stopped me from accepting a job offer as a maintenance manager at a disabled college in Devon, thereby cutting me off from another source of income.
51. After the liver transplant, I had to fight tooth and nail to receive a disability allowance, but I have been unable to receive it since then, despite attending court to prove that I am eligible. I found the court proceedings to be extremely patronising: they neither respected me nor read the medical information I collated to prove that I am eligible for a disability allowance. I receive £19 above the threshold to be eligible for social security and therefore I do not receive anything from the government.
52. I do not enjoy my current life of being constantly ill and in pain; I enjoyed my work, and I was good at it, and I do not enjoy life at home being resigned to a chair.

Section 6. Treatment/Care/Support

53. I feel as if I have lost a decade of my life, particularly because there was a chance that all of this could have been avoided had I received treatment when the GP initially diagnosed me with Hepatitis in 1998.

54. The crazy thing is that I was told not to worry upon my initial diagnosis because, due to blood regeneration, I would recover from my HCV infection within 3 months.
55. I have never been offered counselling or psychological support for being infected with HCV. Had it been offered, it would have been massively beneficial, as I would have been able to find out more about the infection, and how to manage the symptoms.
56. I have, however, received some support for the treatment to my liver problems, but it is only available in Derriford Hospital, Plymouth, which is difficult to get to from where I live in Devon.

Section 7. Financial Assistance

57. I was unaware that financial support was available until a friend of mine told me about Skipton Fund in 2011/2012. He informed that they offer financial support to people in my position.
58. I did initially struggle to gain access to the financial support offered by Skipton Fund, as I was unable to acquire the requisite medical records from Cambridge Medical Hospital, which has since permanently closed. I also struggled to acquire medical records from other institutions.
59. Due to this, when I first applied to Skipton Fund I was rejected, as I did not have enough medical records proving that I was eligible for financial support. I appealed the decision, and managed to gain more medical records, and I had my sisters to write to the Skipton Fund certifying that I received several blood transfusions due to my treatment for rheumatic fever as a child.

60. The appeal was successful and I began receiving financial support. On 14 June 2012 I received a first stage payment of £20,000 and then I received a second stage payment of £50,000 a month later, in July 2012. Since then, I received monthly payments of just under £1200 per month from Skipton Fund.
61. I also received a grant from the Caxton Foundation to have my house fitted with heating; this was particularly important as my wife and I often struggled to keep the house warm enough for me to be comfortable. The grant was also spent on refurbishing my house to make it more accessible for me, including the construction of a downstairs bathroom and a bedroom.
62. I found the support from Skipton Fund to be very good; it had a strong support network and phone line, and the process was personal and tailored to our needs. I found them to be highly receptive and understanding of my situation.
63. Differently, I have a very bad experience with the England Infected Blood Support Scheme (EIBSS), which has taken over from Skipton Fund. The EIBSS do not offer the same level of support of Skipton Fund and the process is impersonal.
64. On one occasion, after I applied to EIBSS for a top up in my payments, they first overpaid £5000 into my account and then they sent me a threatening email demanding that that I paid the money back. The email was extremely strong in tone. The overpayment was a mistake on their behalf and yet they threatened to deduct the £5000 from my payments. They did not offer an apology. I even contacted my Member of Parliament, GRO-C for support during the ordeal but nothing happened.

65. I have found out that EIBSS are emotionless in providing support: they do not have a phone line, they are very impersonal and most of the time they couldn't answer to my questions.

Section 8. Other Issues

66. I have been a member of the Tainted Blood Group for 2-3 years prior to being told that the group was tailored specifically for haemophiliacs.
67. I am not an active campaigner in the contaminated blood movement, but I wanted to get involved in the Infected Blood Inquiry's hearings. I did not attend the Inquiry's preliminary hearings: I was scared, which is down to the stigma attached to my infection and also I did not have the money and energy to travel and to be actively involved.
68. I have not been involved in any litigation about being infected with HCV.
69. In terms of what I expect from the inquiry: I expect honesty, clarity and the truth to be told about what happened. I want the government to properly apologise for being responsible for so many avoidable and unnecessary deaths.
70. What happened was a farce; I find it disgusting that people were still being infected despite the fact that the authorities knew of the risks of infection and did nothing about it. I want the government to admit that what they did was wrong, and to provide a genuine apology coupled with a massive payout for those affected by this ordeal.
71. What happened was a sham and a shame; and it has been quite a ride for 30 years.

Statement of Truth

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

Signed

GRO-C

Dated

18th January 2019