



Witness Name: ALEXANDER ATKINS
Statement No.: WITN00256/001
Exhibits: **WITN00256XXX**
Dated: 16 October 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ALEXANDER ATKINS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 October 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, ALEXANDER ATKINS, will say as follows: -

Introduction

1. My name is Alexander Atkins and my date of birth and address are known to the Inquiry. I am a single man, and live alone in a rented flat, which I pay for with the assistance of State benefits.
- 1.1. I intend to speak about my infection with Hepatitis C, which I contracted as a result of a blood transfusion and conducted during dialysis treatment for renal failure as a child. In particular, I shall discuss the nature of my illness, how it has affected me, and the impact it has had on my life.

Background

2. At the age of 12 I went into acute renal failure, and was rushed to Southern General Hospital, Glasgow to begin dialysis treatment. Thereafter, I was transferred to Yorkhill Children's Hospital where I would receive dialysis three or four times a week. Yorkhill is now part of Queen Elizabeth University Hospital.
- 2.1. I remained there as an in-patient almost continually over the next four years until I received my first kidney transplant. My body rejected that kidney after two years, and I subsequently received another kidney. I

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remained well with that kidney for seven years before my body rejected it and I required further dialysis whilst I awaited a third transplant.

- 2.2. I received my third transplant at around the age of 30, which has remained functioning, despite receiving some damage when I was first transplanted. I have infrequent check ups to monitor this and take immune suppressants to maintain my kidney.
- 2.3. I have also had numerous other surgeries relating to gastric issues: the first and second were both related to bowel blockages and have resulted in 10cm of my bowel being removed. The first took place in the late 1990s and second in 2005. The most recent surgery was in March 2018, where my gallbladder was removed, along with a hernia and a mesh was inserted to keep my intestines in place.

How Infected

- 2.4. Throughout the course of my dialysis treatment, I received multiple blood transfusions. As such, I could not pinpoint the exact one, which infected me however, I believe I was infected at around the age of 13 as I recall going yellow after one transfusion.
- 2.5. A couple of days after that transfusion, the Chief Doctor took my dad into a room in the hospital and said 'your boy's got bad blood but he'll be okay'. He then passed the information, that I had received "bad blood", on to me. There was no formal consultation with my father at that time, from my knowledge there was no consultation subsequently. To this day, a medical professional has never directly informed me that the blood I received was contaminated. Several years later I recall being told I had a Blood Borne Virus around this time.
- 2.6. I found out about my infection entirely by accident; I went for a hospital check up at the Renal Transplant Clinic at the Western Infirmary following my second kidney transplant in the late 1980s/early 1990s. On that occasion, I happened to see the doctor's computer, which was displaying my medical notes on the screen. At the top I saw the word positive. I asked what it meant to which the doctor replied, 'Oh, that means you've got Hepatitis C'. I am unable to recall which doctor this was, and I was not given any information about Hepatitis C at that time.
- 2.7. I have never been given any information on how to manage my Hepatitis C infection. I've done my own research into the symptoms, some of which conflict with the symptoms of my dialysis such as fatigue, loss of appetite, aching bones, and physical exhaustion. At first it was hard to pinpoint whether it was my infection or renal issues causing the symptoms. However, when I had the successful transplant, and still had the symptoms, I was in no doubt what was causing my issues. It was the Hepatitis C virus. I found that drinking alcohol causes yellowing of my eyes, and liver spots and consequently I no longer consume it.

- 2.8. From my research, I have learned about the risk of infection posed to others and have taken appropriate steps to reduce this risk. I kept my toothbrush and razor separate. I subsequently told my long-term partner at the beginning of our relationship so that she could make her own decisions about the level of risk she was willing to take.
- 2.9. I believe that once the medical profession were aware of my infection, they should have told me straight away. Instead, I discovered by default. Further, I should have been told before receiving my first blood transfusion of the risk of infections posed by contaminated blood. As a child, I was not given a choice: either accept the transfusion, or decline and die.
- 2.10. I have numerous tattoos, the first of which I got approximately 14 years ago. I have always told the tattoo artist of my infection so that they can take appropriate care. I have also my ears pierced from the age of 16. Moreover, I received the transfusion, which I know caused my Hepatitis C infection prior to any sexual activity with another.

Other Infections

3. I was not, to the best of my knowledge, infected with anything other than Hepatitis C as a result of my blood transfusions. I was initially told that I had 'bad blood'.

Consent

4. Due to my dialysis treatment and in consequence of it, I required several transfusions and I was never consulted, neither were my mother and father.
- 4.1. I was not told I was being tested for Hepatitis C: the way I discovered my infection (by accident) attests to this.

Impact

5. For almost my entire life, I have felt different from everyone else. I thought it was just myself that had been in receipt of contaminated blood; I thought I was 'the unlucky one'. I have always felt stigmatised, and been concerned if any blood comes near me, or mine near anyone else.
- 5.1. On one occasion, I took my Dad to Barcelona for a Celtic match. I fell over and grazed my knee. Though people were trying to help me, I had to keep them away and tried to catch my own blood to prevent the spread of infection. I felt like I had to put my hands up and tell everyone "I have Hepatitis C".
- 5.2. I am always aware of the potential risk of infection. Due to the steroids I take for my transplant care, my skin is exceptionally thin and prone to

tearing. This means there is an increased risk of my blood coming into contact with other people.

- 5.3. I have a lot of unanswered questions, which have contributed to my mental anguish. This is exacerbated by not knowing to whom I should be angry. I have a great deal of resentment and anger towards both the NHS and the government who have allowed this to happen to me.
- 5.4. Though I am strong of mind, I do try to remember that I am in a vulnerable position and prone to conditions because of my Hepatitis C and my previous renal failures. I constantly live in fear of not knowing how long I am going to be well for and psychologically, I am always afraid of visiting the doctor.
- 5.5. Physically, I am constantly tired and my body is exhausted. I frequently wake up in the night sweating and cannot control my body temperature normally. Moreover, I have liver spots on my arms and gut, which cause itchiness and irritation and I wake up bruised from scratching vigorously. Also, my gums bleed a lot, for which I have no explanation.
- 5.6. I am able to walk, but my body tires easily. I still suffer with symptoms I had prior to my successful transplant, which in my view, I should no longer be suffering with.
- 5.7. I have told my dentist about my Hepatitis C status who has always maintained good and safe practice and has not refused dental treatment.
- 5.8. In March 2018, I had an operation for a hernia. Following this, the scar burst open at one end and as such I required urgent care. I told the nurse about my kidney transplant and Hepatitis C. I then heard her tell multiple people in the ward about my status and was concerned that people would think I'm a drug addict. I was and still am very angry with this.
- 5.9. I was married and living with my wife for approximately 10 years. She would assist with my dialysis treatment. We both wanted children but I was told as a teenager that because of my Hepatitis C, I would be unable to have children. We separated because of my inability to have children and I remain upset that I have not been able to have a family of my own. All my siblings have children however I feel that I have been deprived of the choice of fatherhood.
- 5.10. After my wife and I separated, I entered into a relationship, which I remained in for again ten years. My infection did not have an impact on it, as I informed her of it at the start of the relationship. She knew not to come near me if I ever bled and to take extra care when her children and grandchildren came to visit.
- 5.11. My parents were also angry and emotional. They considered the best course of action to be to restrict the time I spent with my siblings whilst I was receiving treatment. I do think they were overprotective when my

blood could have been exposed to them and this caused different family dynamics because of their action.

- 5.12. Though I can no longer drink, I still go to the pub to see my friends. Occasionally, when people are at my house eating, they have expressed their concern at using the same crockery as me and also using the same teacups that I may have used. Given that not everybody knows, I have to ensure I am careful around them. I do try to keep myself out of situations where I have had to disclose my infection status to people so that I can avoid stigmatisation. I have great concern that people will think I'm a junkie. I have felt like a 'social leper' and different to everyone else; my blood is tainted and people are afraid in case it taints theirs.
- 5.13. In Scotland, some people colloquially call those of us with illnesses such as Hepatitis C, HIV and AIDS as having "The Plague".
- 5.14. I have not been to school since the age of 12. I was unable to attend in part due to my renal failure and in part due to my subsequent infection. It's impossible to say whether I would have been able to attend with the renal failure, but the Hepatitis C infection ensured I could not.
- 5.15. Additionally, I have never been able to work or even train for a job. As a child, I dreamt of joining the Army. Perhaps if I had had a successful transplant and not received contaminated blood, I would have applied.
- 5.16. Consequently, I have always lived on the breadline and been dependent on State benefits. My parents initially received these, but I have claimed them directly since the age of 16.

Lack of Hepatitis C Treatment

- 5.17. I have never received any treatment for Hepatitis C and as such still carry the infection. Following my second transplant in the early 1990s, I was referred by the renal clinic to attend and discuss treatment at the Brownlee Centre at Gartnavel General Hospital. I attended and informed them I had had a transplant previously. Their response was to tell me that they had not had one [a transplant patient] before and as such I was reluctant to receive any treatment at that point in time. As such, I did not want to be a human guinea pig. At that time, I also was unaware of how successful the kidney may be and didn't want to risk hindering its chances of success.
- 5.18. When the second transplant failed, the Brownlee Centre asked me to attend again, but I was very unwell and in receipt of dialysis treatment at that time and didn't want to take any medication that would make me feel worse.
- 5.19. Being a transplant patient is an obstacle to receiving treatment; my transplant has always been my priority. This has meant I have been less

inclined to partake in courses of treatment, in case it jeopardised my new organ.

- 5.20. I am unaware of any treatments I ought to have had to treat my Hepatitis C. I am currently on an assessment to decide which form of treatment I should receive to treat my Hepatitis C. This treatment has not yet begun and I have a second consultation in November 2018. I hope this will ascertain which course of treatment I will receive.
- 5.21. I have had no mental or physical effects of Hepatitis C treatment, as I have not received any.

Treatment/Care/Support

6. My infection with Hepatitis C has caused some difficulties in my ability to obtain medical treatment. I have had multiple major surgeries for gastric issues. Post-operation, my pain medication is usually restricted to reduce the risk of further damage to my liver. Consequently, I am left in considerable pain during my recovery period.
- 6.1. This pales in comparison to the poor treatment I have received by medical staff. On one occasion at Western Infirmary, I went for an operation and had duly followed the rules to be nil-by-mouth from the night before. I was admitted to a ward in the Renal Unit in the morning, but by the late afternoon, still had not been operated on. I spoke to the Head Anaesthetist who kept walking past my bed and asked her why I had not yet been seen. She informed me that I was being operated on in the last surgery time of the day, because they would need to clean everything I came into contact with, due to my infection.
- 6.2. This became the standard procedure, and something I came to expect any time I needed hospital treatment.
- 6.3. Counselling and psychological support have never been offered to me, nor have I requested it.

Financial Assistance

7. In 2001, I visited a lawyer, because I knew someone had shafted me and hoped there would be some way to be compensated for this. He told me that he would take my case on, but he needed to look into one thing first and that I should go back a week later. He then told me that the thing he had looked into meant he could not help me further. He said, the government had a block on payments and my best advice to you is to watch the news. He told me that he had passed my details onto a third party. I never heard from him again.
- 7.1. I believe he passed my details on to the Skipton Fund, as I received a letter from them in 2004, which informed me that I was eligible for a Stage 1 Payment. This was to the amount of £20,000 and was paid that year. In

December 2016, I then received notice of being given an additional Stage 1 payment, which was to the amount of £30,000.

- 7.2. Since the switch to Scotland Infected Blood Support Scheme (SIBSS) in November 2017, I have been in receipt of £175 paid monthly. I also received a £1,000 winter fuel payment over the Winter 2017 period.
- 7.3. SIBSS send you a letter confirming eligibility at the start of each year. They check your evidence is the same and ask for three months of bank statements to ensure income and expenditure has remained the same.
- 7.4. I did not have to make any form of application to the Skipton Fund.
- 7.5. Although I have received £50,000 from the Skipton Fund, I can't help but feel that this is the amount to which they have valued my life – at £1,000 a year for every year I have been alive.
- 7.6. If I had received payments earlier, I would undoubtedly have lived a better life. I have always been in debt or owed money to people to the point where I was unable to buy day-to-day necessities and also to pay for the fuel costs in my house.
- 7.7. In 2010, I saw an advert on the television for a debt management scheme, which I enrolled in. It greatly helped me reduce the amount I owed and, the payment of £20,000 helped clear my debts. Then, the additional £30,000 payment has improved my quality of life.
- 7.8. Apart from the details above no person at any time has sat me down and told me about any financial help from the Government, Charities or Trusts. I understand that I could have had help with washing machines and household goods or help with my general welfare. Nobody even informed my parents. I could have had some form of better lifestyle if they had.

Other Issues

8. My illness did not just impact on my own life, but on the lives of those around me, too. My mother and father were both greatly affected, as were my siblings, extended family and friends. Sadly my mother died in August 2018, before I got to inform her of the announcement of the Inquiry and she will never know the outcome of it. The fact that my mother will not know has affected my grieving process greatly.
- 8.1. I cannot help but feel that due to my previous renal failure and now my Hepatitis C infection, I am always going to be reliant on the NHS. I find this hard to reconcile in my mind as I consider them to have damaged my life considerably. I am concerned that this may happen again. Despite being unable to trust them, they are my only option – the other would be my death.

- 8.2. I have also found that when I have done research into Hepatitis C, the majority of it pertains to haemophiliacs, which I have found to further my feelings of isolation. I think many transfusion recipients have 'slipped through the net' – that is to say that they do feel that there has been a lack of recognition of infections from transfusions.
- 8.3. I would like the Inquiry to find out who made the decision to import infected blood; undoubtedly, there are pertinent politicians who sanctioned this and must be held accountable.
- 8.4. I would also like to know why it has taken six governments for an Inquiry to be undertaken. Penrose was inadequate and further enhanced my distrust in the government's policies.
- 8.5. I believe strongly that I would like to have been an organ donor at the time of my death. However, I feel that as no one wants my organs whilst I'm alive, no one will want them after my death.
- 8.6. I entered Yorkhill Hospital with one life threatening illness and left four years later with two.

Statement of Truth

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

Signed

GRO-C

Dated 17/10/2018