

Witness Name: Simon Hamilton

Statement No: WITN2339001

Dated: 11<sup>th</sup> March 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF SIMON HAMILTON

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I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12<sup>th</sup> December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I Simon Hamilton will say as follows.

#### **1. Introduction**

1. My name is Simon Hamilton. My date of birth and address are known to the inquiry.
2. I am a haemophiliac and have contracted Hepatitis C ('Hep C') through contaminated blood products.
3. I am the Chairman of Haemophilia Northern Ireland.

#### **2. How infected**

1. I had a number of bumps and scrapes as a child and would receive Cryoprecipitate ('Cryo') for this. I remember that when received Cryo it would be given to me through an intravenous drip.
2. When I was in my mid 20s I received a blood product called Haemophil. At that point I was taught to self-inject. We would attend Queen's University students' RAG day and I recall at school that we would mess around with the syringes, we would run around and squirt each other with water from the syringes.
3. I am now aware that I received synthetic blood products which I now know were contaminated products. I await provision of my medical records and I will need to refer to these medical records in order to confirm which products I received.
4. When I was a child I would go to the Royal Victoria Hospital in Belfast. The Haemophilia Centre was based in the Royal Victoria Hospital for a long time. The Centre then moved to Belfast City Hospital. Since the 1980s, I have received my treatment at the City Hospital on ward 10, a ward that was shared with leukaemia patients.
5. When I was quite young probably in Primary School, I bit my tongue. I had a huge haematoma on my tongue. I experienced a number of complications as a result of this. I remember that day I had either Cryo or a different blood product administered to me, the doctor really struggled to find a vein. I recall it took around fifteen attempts to find a vein that day.
6. I recall one specific occasion when I was 16, I was knocked down whilst crossing the road. I remember when I attended the hospital on that occasion I received Cryo. The Hospital I attended that day I think was the Belfast Hospital for Sick Children. I also had to receive plastic surgery after the bleeding stopped.

7. I had three wisdom teeth removed when I was in my late 20s/early 30s. I asked if I could have those removed without receiving factor products. I recall the bleeding would not stop, due to the perpetual bleeding I gave in and had Cryo administered. In my thirties I had both Cryo and Haemophil administered.
8. I was unable to play contact sports due to the bleeding in my joints. I was very level-headed about this and would not take a chance as I really did not want the bleeds.
9. In regards to sports that I take part in now, I am a keen rower. I have rowed for many years. I have also rowed at a competitive level at international and British Masters level. I like to keep myself as fit and active as possible. Rowing has enabled me to stay fit without running the risk of having a severe bleed. I believe that people should live by a philosophy of not doing things that are reckless especially when they are haemophiliacs.
10. I recall whilst working at an accountancy firm, one day we played five a side football. One evening during a match I was leg checked, the haematoma that developed on the side of my thigh was like the size of a bouncy ball. I was admitted and received either Haemophil or Cryo. I will need to refer to my records to confirm which one of the two I received. I am not certain on what doctors I was under the care of that and will need to check my medical records.
11. The haemophiliacs at the hospital that day were a mixture of being infected with HIV, co-infected or just Hep C. We were told by the medical professionals in the late 1980s that haemophiliacs were found to be contracting HIV and Hep C. A letter went around which asked if people wanted to know if they were HIV positive or not. This is my recollection of how people were offered to find out if they were HIV positive, this coincides with my brother Nigel's recollection of events. This was headed by Dr Elizabeth Mayne, I cannot give you a precise date as I will need to refer to my medical records, further clarity

will be provided in my supplemental statement once I have viewed my records.

12. I found out that I was infected with Hep C from the Royal Victoria Hospital Belfast. I was called in for a meeting around the period 1995/1996. I had received a letter which invited me to come to the haematology unit. My brother Nigel also received a letter to attend the hospital that day. I remember vividly that day that the haemophiliacs around us were stiff and had problems walking. I remember saying to Nigel that we looked like super humans in comparison.

13. I found out that the infected batch I had been given was in 1986 and this would coincide with the occasion that I received blood products when I had been leg checked during the five a side football match

14. I recall that my wife, my son and I were invited back to the hospital for a second appointment. On that occasion my wife and son were tested but their results came back negative. I had my gallbladder removed about 5 – 6 years ago. I had treatments at the Royal Victoria Hospital. This was a result of the Hep C treatment, I ended up having higher blood pressure and spasms in my gall bladder which required it to be removed.

15. A short time after the antiviral treatment ended I had a brain haemorrhage which was life threatening.

### 3. Other infections

1. I have cirrhosis of the liver from being contaminated with Hep C and have to attend the hospital for regular check-ups to monitor whether I have developed liver cancer.

2. It was during 2012/2013 that I was diagnosed with cirrhosis. I was told that I had this during a Hepatology appointment and informed that they would monitor me every six months.

3. The second treatment I had for cirrhosis was in 2015. Mentally and physically I was considered to be in good condition and the haematologist consultant Dr Benson had the treatment administered at the Haematology clinic at Belfast City Hospital Bridgewater Suite.
4. However, I am well aware that cirrhosis will eventually lead to death. It often leads to liver cancer.
5. The hospital is always wary of tumours developing on my liver. I am considered to be at high risk of contracting liver cancer. I have had two MRIs after shadows were found on my liver. The left corner of my liver is clearly scarred and is checked carefully at the six monthly appointments. I also have blood tests that test for cancer and a six monthly scan. These also give a reading on the calcium rating on my liver.
6. The second treatment I had was successful and the Hep C was suppressed. However, the second treatment had a significant effect on my health from and I was left with deleterious after effects. The side effects of the anti-viral treatments caused me to have high blood pressure and a bleed on my brain.

#### **4. Consent**

1. There was no information of the risk of being exposed to Hep C. After a considerable period of time afterwards it was only then that we were told that there was a problem with the blood products haemophiliacs had been receiving.
2. My brother found out that he had been infected through viewing his medical records. I believe that doctors had knowledge and awareness of the contaminated products. I believe the doctors were selective about when they discussed that blood products were contaminated for a substantive period.

3. I was not made aware of the consequences of Hep C until I developed cirrhosis over the past seven years. I now have to have a test every six months to determine if I have liver cancer.
4. Dr Mayne gave me advice regarding the Hep C in 1996. We had all been infected but we had the option of knowing if we were infected with HIV. I cannot remember if there were other tests performed but what I do recall being tested for HIV. I remember being very surprised that we were given the option of not knowing.
5. Nigel and I wanted to know more about Hep C. I remember being told that it would have an effect on my whole life. I did not feel and still do not feel as though I was informed very well as to the consequences Hep C would have on my life.
6. There was a perception the Hep C would not take effect or have an impact when I was diagnosed. I did not come out of the hospital on the day I was told thinking it would change my whole life. The way we were informed definitely played down the true reality of what it was like to have Hep C.
7. If the hospital had knowledge of us having Hep C earlier than we were told then we should have been given the information earlier on and at the earliest point in time. While all of this was going on people were signing their own death warrants, two of my cousins contracted Hep C and died from this.
8. I believe the amount of information we were given was all controlled. I believe we were guinea pigs. People continue to die and there are still live specimens like myself and Nigel. I sometimes think the Department of Health wanted us to be Guinea Pigs.
9. If I die from cirrhosis or liver failure I would be a specimen which I believe some doctors wanted us to be.

10. I live my life on a basis of six months at a time as I have tests every 6 months to check whether or not I have cancer on my liver. The hospital has given me reassurance that I will be eligible for a liver transplant until the age of 70. This is one of the main reasons why I try and keep myself so fit and active. After that if I develop cancer they have given me no hope of a transplant at this stage. That's a lot to deal with when you are being checked every six months and know that your liver has bad scarring.

11. I fear will eventually become a specimen of a system that has failed.

## 5. Impact

1. In all honesty, I feel as though the way people have died from this contaminated blood it is like a game of Russian roulette. I find myself getting more and more upset as the years go on.
2. I had bottled up my feelings relating to this for years and I have only just realised the true extent to which this has impacted me.
3. I was very upset when I went to see Dr Benson this year. I was referred onto a clinical psychologist. I attend the clinical psychologist and discuss how I feel.
4. I also receive reflexology and therapy through Macmillan Cancer Society. Upon receiving my diagnosis for cirrhosis I was never offered support. Like I say previously in my statement it was only recently that any support was actually provided.
5. I have developed a great fear that I am going to die ahead of schedule due to me contracting Hep C through the contaminated blood. The thought of turning completely yellow, losing your mind, your veins bursting in your abdomen, all of this happening whilst you have to sit there and wait to see if there is a liver that is a match for you.

6. Mentally trying to compose yourself and process this in your brain whilst still having aspirations for your life is beyond difficult. I cry for those whose lives have been lost and wasted as a result of this contaminated blood.
7. I feel that every human being regrets the things they never did. They regret not making time to spend with their loved ones. For contaminated blood victims these are the kind of thoughts they have to live with everyday. The quality of their lives has changed dramatically as a result of receiving this blood contamination.
8. I always have the thought that I am in this group of people that could die. These are the realities for those who have received this contaminated blood.
9. I recall having treatment at the dental department of the Hospital in Belfast, this is where I had to attend to receive dental treatment. The X-ray procedure was very stigmatizing in the early days after my diagnosis. Radiologists refused to carry out the x-rays and the dentist had to do it because they thought I would infect them. The way they treated me made me feel so unclean and an outcast.
10. Every time I feel unwell or have a twinge in my stomach area I put my hand there to press it and double check that I am ok. I have been lucky enough not to have experienced a swollen belly from the cirrhosis.
11. Since the Hep C has cleared I have noticed that I have so much energy. Hep C now lays dormant in my body. However, I will always have cirrhosis and live under the shadow of risk that I might develop cancer which would change the course of my life once again.
12. It has worked for me to be open with my current employer. My friends are aware of what has happened to me. I am aware there are people out there who don't understand and don't think you are a clean person, some people assume that you are dirty and drank yourself to having cirrhosis.



13. I have never experienced mistreatment from any of my employers in regards to my Hep C.
14. One of the problems I encounter when I have informed people I have cirrhosis is people assume you are an alcoholic or have contracted this through heavy drinking or having sexual intercourse.
15. I believe that people who have received this contaminated blood should make the courageous decision to not hide away. I am glad that I never hid away. I have been lucky enough to not be disadvantaged educationally. I have degrees and teaching qualifications although I will add that some of my education advantage is owed to my social background but also the sacrifices made by my parents because they wanted to protect me by providing opportunities to be educated and get non-manual work.
16. I have had time off work as a result of the Hep C. In total I would say I have had two years off solely from being unwell due to the Hep C and the treatment for this. When referring to complications with my haemophilia and Hep C, I would make an educated guess that I have missed four years in total.
17. I am lucky in the sense that I have a good job that pays well. The last 15 years when I have been off with Hep C my employer has been great. My contract allows me to take a period of six months of work paid. I recognise that I could be a lot less fortunate if I did not have employment in my current role.
18. The impact on my family has been considerable, especially my wife. She has had to go through a lot of trauma. We are people of faith. The thought of anything ever happening to my wife is desperate, I could not imagine life without her. The way that she copes with everything that has happened is admirable.

19. I had a brain haemorrhage a few years ago and it was thought that I was going to die. This was after my second round of anti-viral treatment. Also this was the only time I have ever seen my wife break down and cry.
20. My wife is so strong. She has managed to keep on the straight and narrow emotionally despite everything. I cannot put into words how much of an impact this has had on her. When I saw her crying I knew I was in trouble. It is a reflection of how strong she has been.
21. My son worries, if we are in the car for example and I sigh he will say "Dad are you ok?" He is aware that the state of my health can change quite quickly. In his own way he really looks out for me. He does not want to show that he is worried but he is.
22. What has happened has had a huge impact on my mother. She loves me immensely and she often blames herself for myself and Nigel having haemophilia. My aunty felt the same way as my mother, her two sons passed away from Hep C.

## **6. Treatment/care and support**

1. I received treatment for my Hep C through Dr Gary Benson at Belfast City Hospital. Dr Benson told me that he wanted me to have the treatment following the first unsuccessful treatment in order to give me the best chance of survival.
2. I have a Consultant Hepatologist, his name is Dr **GRO-D** I did not tell Dr **GRO-D** that I was going to be receiving the second treatment as he had been telling me for months that the treatment was unavailable and was unaware that Dr Benson was putting me on the fast track to receive this treatment.

3. Dr Benson put his job on the line for me, he wanted me to be given the chance with this treatment and save my life. I had the treatment and it worked on this second occasion.
4. A few months after the treatment I had an appointment with Mr **GRO-D**. He told me that the treatment that I had received under the supervision of Dr Benson had now become available. Dr **GRO-D** informed me that I was at the top of the list. I told Dr **GRO-D** that I had already received this treatment and he was lost for words.
5. The treatment I refer to is that of Virafirin. I was at first given Ribavirin but due to the determination and goodwill of Dr Benson I was given the super treatment that is Virafirin.
6. The treatment stops the deterioration of my liver. If I had waited for Dr **GRO-D** treatment I would have suffered more and my liver would have deteriorated further before getting the treatment that worked. That would have been definitely bad for me and my family and my liver prospects.
7. I still go for an endoscopy, the results of this at the moment are reading as ok. The Hepatologist/radiologist always looks at the left side of my liver. They have found benign growths on my liver. However the treatment that was ok'd by Dr Benson worked for the Hep C.
8. This was the last time someone was treated for cirrhosis in Belfast City Hospital and strained the relationship between Dr **GRO-D** and Dr Benson. However, without the help and determination of Dr Benson my life may have taken a different turn as I would have been suffering from active HCV for at least two years longer.
9. In terms of counselling, I have been offered this since the Inquiry started. I went for a meeting during September 2018 which discussed the Inquiry and for the following few days I was so unwell. I had been so overwhelmed by what had happened to people, I was so overwhelmed with emotion.

10. I just think of my cousins who were haemophiliacs and had died from Hep C. They were younger than me, they have been completely forgotten about. I get so upset over the fact I lost my two cousins to Hep C and the reality that I could have faced the same fate as them.
11. The cirrhosis I have is said to be under control but the swollen veins I have are still there.

## **7. Financial assistance**

1. I received money from the Skipton fund. I cannot recall what year this was but I specifically remember having to sign a waiver stating that I would not sue the Government. I received £25,000 as a result of signing the waiver.
2. When I developed Cirrhosis, I received stage two of the Skipton fund. BSO has been formed which takes over from the Skipton fund. I ask the BSO to pay me quarterly. They usually pay victims monthly, however I like to be more strategic with my finances.
3. I have not faced any obstacles when trying to obtain financial assistance.
4. I am contemplating retirement soon. Therefore this money can help me. When Nigel nearly died from his liver transplant it made me reconsider how I want to spend my time, I want to live life to the full and enjoy as much time with my loved ones as I can.
5. Individuals who have received contaminated blood should not encounter issues when applying for benefits. All of this is the fault of the Government, they should own up and allow put a system in place that allows contaminated blood victims access to benefits. I have heard about the issues victims have had with PIPs, its ridiculous, the Government should be making payments responsibly.

## 8. Other Issues

1. As Chairman of Haemophilia Northern Ireland I try and provide support to haemophiliacs and the sharing of information with young families is very useful, providing advocacy and support.
2. We have been able to provide support to victims of the scandal. I feel as though it has been a reluctant process as the Government do not want to put their hands up and admit to what has happened.
3. The Government knows exactly what was happening at the time. The fact that waivers were given to victims to sign shows guilt and a calculated form of forward planning. Also, when people are financially vulnerable and psychologically vulnerable which many people who have contracted contaminated blood are, they would take any payments even if that meant signing waivers. The Government took advantage of their vulnerable situation. Specifically, I believe financial assistance that is in place for widows requires desperate reform.
4. I have been in meetings with the Junior Health Minister and the cabinet Office Minister and I am really hopeful that the Government will heed Sir Brian's request that those infected and affected will receive an uplift that permits them to live not simply exist.

Statement of Truth

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

GRO-C

Signed.....

Dated..... 11 / 3 / 2019 .....