



Witness Name: Christine Norval

Statement No.: WITN2234001

Exhibits: N/A

Dated: 21/11/2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CHRISTINE NORVAL

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

I, Christine Norval, will say as follows: -

Section 1. Introduction

1. My name is Christine Norval. My date of birth is 1967. My address is known to the Inquiry. I am currently retired and before I retired I was a physiotherapist. I had issues with my arm after having treatment for breast cancer that prevented me from being able to continue in my role. I intend to speak about my husband, Bruce Norval. In particular, I intend to speak about the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

Infected Blood Inquiry
Fleetbank House, 1st Floor, 2-6 Salisbury Square, London EC4Y 8AE
contact@infectedbloodinquiry.org.uk
Freephone 08081691377

2. I have given a statement in relation to my husband Bruce Norval. I have been married to him for just over 28 years. We married in 1990 have been together for 30 years overall. We have two children. We had Catriona in 1991 and had Robert in 1997.

Section 2. How Affected

Bruce's haemophilia

3. I first became aware of Bruce's haemophilia on the day we met. We met in the August of 1988. We were both working for an agency in London as auxiliary nurses. After a shift, we went for dinner at my flat. When he told me, my first response "Oh, have you got AIDS?". This is because around 1984 or something like that, it was all over the press about haemophiliacs all having HIV or AIDS. Bruce was very gracious in his response and said no. Bruce was not aware of his having hepatitis C at this point. He was ill, but he did not have a diagnosis for what was wrong with him at that time. Doctors had a tendency to tell him that the symptoms he told them he had were all in his head.
4. Bruce suffers from haemophilia B which is also known as Christmas disease. In order to be treated for this he has received Factor IX treatment. Bruce's haemophilia is of a moderate severity.
5. Bruce was initially treated in Edinburgh as a child as far as I understand it. I believe that whatever hospital he was treated at initially has since been knocked down. His mum was a spontaneous carrier so he was not diagnosed until he was three years old. I believe this may have been discovered when he had surgery for a hernia as a baby. After moving to Inverness (aged 11) he was be treated at Raigmore hospital.
6. I believe that in the 80's before I knew Bruce, he did study to be a nurse in Dundee but he got very sick. This was right at the outbreak of the AIDS crisis in the early 1980s. He was viewed by those involved in the

training as an "unacceptable infection risk". I do not believe he was able to have a test for HIV at that time. He was forced to move back home to Inverness. Bruce has said that he was getting threatened and Mums and Dads of his friends wouldn't let him in their house because of knowing that he had haemophilia and assuming that he had HIV.

7. In around 1984 or 1985, Bruce moved to London to become a roadie. This was no small part due to the stigma. Everyone knew everyone where he was from and he needed to get away from that environment where people pre-emptively judged him purely because of his haemophilia. When he was first in London, he lived in very poor accommodation and there was nothing that was very steady. At one stage, Bruce was homeless and lived under what is known as the Westway. He would only be able to get temporary accommodation when he was ill or beaten badly, I believe he told me he spent a good two years in a cupboard in a hotel before getting a council flat.
8. At some stage between 1985 and 1987 Bruce was able to access HIV testing through the Terrence Higgins trust while working for a band with Jimmy Somerville. It was a contact from the band that made sure he was able to get this test. This came back negative. Bruce has never had an NHS HIV test to his knowledge.
9. At the time we first met, they didn't really have any home treatments and it was only really when he had injuries that he would receive treatment and he would go to hospital for this. I believe he was referred to St Thomas' Hospital in London for his haemophilia treatment in 1989 or 1990. I believe that he started home treatment in around that time. One of the consultants who treated Bruce at St Thomas' Hospital was a Dr Savage, who I believe has since died. Bruce has been on some form of treatment as long as I have known him. Bruce is now on lots of different treatments for his haemophilia. I do not know the name of them offhand, but these last longer in the system than Factor IX would have back when he first received it.

10. Bruce is allergic to a lot of treatments and has to have his first treatment of any particular course of treatment in hospital due to them having to watch if he has any allergic reaction to this treatment. In the past he has gone into anaphylactic shock due to having had an allergic reaction to treatments.

Bruce's diagnosis with hepatitis C

11. While Bruce was still a student studying to be a nurse in London, he started to become unwell. This would have been around 1989, roughly 6 months after we met. The symptoms he had at that time were nausea, vomiting, fatigue and brain fog. He asked doctors for answers for what was wrong with him and they would tell him nothing was wrong. The doctor's treating him at that time would have been from the haematology team at Hallamshire Hospital. They would call him an HIV wannabe. He later changed haematology centre to St Thomas's Hospital. As far as I am aware, there was no support offered by the college. He couldn't continue as a nurse. He was struggling with the symptoms of hepatitis C without yet having had it diagnosed at that time. We were in London throughout the time when Bruce was studying at college. He struggled to study and with any written work. He had to have lots of time off, to the point where he just could not continue.
12. Within a year of us meeting we went to the Haemophilia Society and spoke to someone there called David Watters. He sat down with us and helped Bruce fill in benefits forms because he could not work. After that was when Bruce transferred his treatment to St Thomas' Hospital.
13. I recall Bruce having had a dental extraction at St Thomas' at the end of 1989 or start of 1990. I believe that 1990 is more likely. After he had the extraction, a stitch came out, and we had to go back to the hospital on the tube. He was spitting blood. It took forever for the dentist to see us and that seemed off. We advised the dentist that he was HIV

negative (based on the test Bruce had arranged as described above) but the dentist stated he needed to discuss his treatment with his haematologist before re-stitching his mouth (I believe this may have been before Bruce's Hepatitis C diagnosis). He was treated as a leper. This is the worst bleed I can remember him having in all the years I have known him.

14. In the early years we really did struggle at the time when Bruce could not work. I was a physiotherapy student at that time too and was living off of a student grant and had around £6 per week, as well as paying rent. Bruce also received benefits at this time. When we got married in 1990 we used the money from our wedding gifts to pay off debts and rent arrears. We got a letter at one point; it went to the stage of threatening eviction. Bruce had payment plans in place. This was tough for us to deal with because I believe at some stage the landlord or the person collecting the rent got the dates wrong and it was all generally a very tough time. All of this time we were told by medical professionals that he didn't have AIDS so there was nothing to worry about – but he was unwell and not getting any better.
15. I remember that Bruce had an issue with his sacroiliac joint and we explained that to a doctor, using that medical term. The sacroiliac joint is where the back joins the spine. The doctors told us that we should not use medical terms. I do not remember his name. The doctor gave us a hard time and belittled me for explaining his issue in that way and I believe that was one of the early factors in creating the distrust we now have for doctors.
16. In terms of when Bruce was diagnosed with hepatitis C, Bruce has said that it was in 1990 was while I was pregnant. He said that he was told at St Thomas' by a doctor there. I vaguely remember that he told me that he had been told as part of a conversation with a doctor while he was on a public staircase with the doctor saying "Don't worry about it" and that "There was nothing to worry about". It felt as if the doctors were

trying to brush us off. I do not recall exactly when Bruce told me about his having hepatitis C, and I was not with him when he was told. I believe he told me very shortly after he found out. It's not a pleasant memory, so I think I may have blocked it out. I do recall going with Bruce for a follow up appointment after.

17. I am not sure how we both felt after Bruce's diagnosis, although I am sure that he was upset about it. One of the difficulties was balancing the fact that I trusted doctors and they were saying not to worry about this being passed on to me, while at the same time having dealt with the fact that doctors said that there was nothing wrong with Bruce when there clearly was. This did put a strain on us.
18. I believe that Bruce was part of a trial group being tested for hepatitis C, and the test was relatively new as far as I am aware. It was all very difficult for us at the time and the strain could have caused us to separate if we hadn't been planning our wedding, and if I hadn't been pregnant. I do not recall any information being given about any risk of hepatitis C being passed on to the baby, and I do not believe that I was offered a test for hepatitis C.
19. When I went for an antenatal appointment I do recall being offered an AIDS test. I believe I was tested for hepatitis C after Catriona was born, and this may have been in 1992 or 1993 that I actually had the test. I can remember getting the results while I was at work. We had moved to Scunthorpe by the time that I was tested. I remember I did go to a registrar in Sheffield who told me that there was a slight risk of hepatitis C being passed on to me, and to avoid sharing toothbrushes. He did also suggest barrier contraception.
20. Cross-infection was always a concern. Bruce was always very concerned about it and was always worried about blood spills. I used to help Bruce find a vein when he was having his haemophilia treatment, but we stopped that in 1992 or 1993 and he did this himself.

21. I do not believe that Bruce was told how he came to be infected. At some stage I do recall that there was an inference that Bruce was infected when he was being treated for his haemophilia, although I do not recall exactly when or how this was communicated. There has been a mention that Bruce may have had hepatitis when he was five years old and that he may have very yellow and he thinks his Dad got the same hepatitis. As far as I am aware no one looked at whether or not this was something that had come from haemophilia treatment.
22. Even when Bruce went for interferon treatment in the 1990s (see below) there was no advice about how to deal with his hepatitis C. I just remember the doctors saying don't worry about it and nothing else was really offered. It felt again like a brush off. I feel that what advice was offered was inadequate because there was not much advice at all. Bruce was petrified that he could have infected me or Catriona. I do not remember being tested then. I was tested many years later, before Robert was born, and I was negative and such I knew our children would be negative.

Section 3. Other Infections

23. Bruce was infected with Hepatitis C. I believe he had other types of hepatitis. He has antigens to Hepatitis B. He has had a vCJD exposure notification letter which was a notification letter when it was thought that a new variant of these could have been transmitted. I think we were up in Inverness when Bruce received the vCJD letter, and it would have been around 2002/2003 that he got this letter. I remember Bruce doing a radio interview about this. Bruce had actually flagged up the risk for haemophiliacs contracting vCJD, but was told that he was scaremongering, before this letter came out. He also, at one point, ended up with Epstein-Barr infection. Bruce had glandular fever as a child and as a teenager, and I also caught it (presumably from Bruce)

in 1989. The symptoms of this were fatigue, brain fog and getting other infections. I recall that I nearly had to resit a whole year at college because I was ill with this, but I did manage to scrape a pass. *As far as I am aware, Bruce was tested for HIV before I met him through the Terrence Higgins Trust. I believe this would have been at some point between 1985 and 1988.*

Section 4. Consent

24. I recall that Bruce was part of a study for a research project on haemophilia in around 1990 when I was pregnant. I believe this was a clinical trial of a test for Hepatitis C. I remember there being some concern at the time about the accuracy of the test because virtually every haemophiliac tested came back with a positive result. There was surprise in some quarters from what Bruce told me, but he was not surprised. At this point Bruce was just desperate for a diagnosis and to know what was wrong; to prove that he was not just going crazy.

25. Bruce does believe his blood was tested before this trial of the hepatitis C test, before he was made aware of having hepatitis C and without his knowledge or consent. He was part of that clinical trial. I believe that prior tests may have contained information about his diagnosis which he or I knew nothing about. He had blood taken at haemophilia centres a lot and that could well have been tested without his knowledge. There was certainly ample opportunity to test his blood without him knowing. We have now received his notes from various hospitals and we will study them to see if they shed any light on him being tested without his knowledge prior to 1990. I have previously seen some medical notes that state that Bruce has overstated the symptoms, which was ridiculous far as I'm concerned.

Section 5. Impact

26. In terms of Bruce's symptoms he had these from when we met, before he was diagnosed. He was generally in bad health. Shortly after we got together I contracted glandular fever from Bruce. I struggled to finish my studies because of having glandular fever. I went from the top of my class in first year to just simply being able to scrape a pass.
27. Bruce's diagnosis in 1990 gave a reason for Bruce having been so unwell that we did not have before. I was still encouraging him to get back to work at that time as the doctors said it was nothing to worry about. At one stage, Bruce worked for Harringay Council in the poll tax office. Bruce was working there just before we got married; we got married in the summer of 1990. He worked there until he joined me in Yorkshire in November 1991. This was a welfare rights type job. He was involved in trying to help to get people the correct benefits so they could pay their poll tax. I think he quite enjoyed this job, even though he thought he wouldn't. I believe this was fulfilling for him because it made a difference to other people's lives.
28. When we got together, our aim had always been that, if we had a child we would share the parenting and work. I wanted to be a mum and work part-time. We had planned to share all parenting duties. It became obvious that we would not be able to do this when Bruce's health deteriorated and he was not able to work. This completely blew our plans out of the water. I am a pragmatist so I just felt this is how it was. I feel hugely that I missed out on our children's early lives. I recall that when we lived in Scunthorpe Catriona had a childminder called Maureen, and sometimes I would come home from work and Catriona would call me Maureen. I used to ride ponies at that point and I hoped to have the money to continue doing that, but we simply couldn't afford that. It put a huge strain on our relationship, since we could not live how we had hoped. Bruce felt horrendous and it changed everything. I am not sure if I had started on antidepressants at that time, I was in counselling but my mental health was not good. I was in counselling through going to my GP.

29. When I had my first antenatal appointment when I was expecting Catriona, I said that Bruce was a haemophiliac. I recall that the junior doctor treating me at the time said, "Do you want an AIDS test?. It would have been around 1990 when Bruce was diagnosed with hepatitis C, when I was pregnant, and we married in the October of 1990.
30. Catriona was born in Lincolnshire as we had moved there and once she was born Bruce's health then dipped again. Suddenly I was having to drag him out of bed. When I was looking after the baby it was like I had two children to look after. I had gone up to Scunthorpe for my sister's wedding and Catriona was born early while I was up there. We moved to Scunthorpe 6 months later. I stayed with my parents for a couple of weeks before going back down to London to Bruce, with the baby.
31. In terms of the symptoms Bruce suffered from his infection, I recall that he had flu-like symptoms. He would have horrendous night sweats. With these horrendous night sweats we would notice that sheets and bedding would be dripping wet some nights. We would sometimes have to get up in the middle of the night and change bedding because of this. Bruce also felt the cold quite badly and did not go out much. He never had much energy and hardly went outside. This was a struggle for him. We had a lot of time spent together watching TV and renting films from Blockbuster. He also had episodes of vomiting multiple times per day.
32. I recall reading medical articles where it was stated that all haemophiliacs were alcoholics due to their liver damage and there was certainly no inference that there was any blame to place on NHS.

33. Bruce and I had moved to Scunthorpe in Lincolnshire in November 1991. Catriona would not have been quite six months old. *(check dates)* Bruce had a lovely council flat in London but when we transferred this to a house in Scunthorpe we did not realise it was on an estate that had a very high crime rate. We did a council house transfer to move there, not realising that we would end up on the Sink Estate, which was known to be a bad area. We could not get childcare in London and it made sense to move there. It was closer to my family, giving us a wider support network. I was able to get a job as a physiotherapist there. We ended up moving to a part buy house after we were burgled four times, although there were also multiple other attempts. I believe that when we were in Scunthorpe, Bruce was mainly treated at Sheffield. He was treated there by a Professor Eric Preston and Mike Makris. Bruce respected them. He thought that he had a good rapport with Professor Preston and that Mike Makris was supportive. Generally he found being treated by them to be a positive experience. The care centre there had physiotherapists and I recall at one point Bruce went in for a week of intensive physiotherapy. This care centre was also where Bruce went on to receive interferon treatment.
34. There were a couple of episodes where Bruce got into bad car crashes in Sheffield and he had chest pains and cardiac problems. These were just part of the various symptoms he had at that time. I was in Scunthorpe Hospital working as a physiotherapist. . At the time Bruce was working in Doncaster as an occupational therapy assistant. I had to get my father to take me to Doncaster when Bruce had been involved in one crash to see Bruce and my boss asked me to "book annual leave for the afternoon". Bruce suspects that he lost his job due to his sickness record. This was a fixed term contract that was not picked up beyond the fixed term. He was applying for jobs all the time, and in particular had an interest in social services and admin roles. He had lots of interviews because he was registered as disabled. He was let down every time.

35. In terms of childcare at the time we paid for private childcare. Our childminder, Maureen, was a retired nurse who worked for us five days a week. She looked after Catriona from the age of 6 months until when she started school. It was only my income coming in and we just had to manage with my wage and the benefits that Bruce received.
36. Our situation had a huge impact on our relationship. We had thought of buying a house before Bruce's difficulties finding work. We were afraid of the implications of having a mortgage in case Bruce was not around to see the following year. We stuck out that council house for as long as we could.
37. I recall that Bruce had Interferon treatment when we were in Scunthorpe. In 1994, following the burglaries, we moved to a village nearby Scunthorpe. I believe in 1993 or 1994, there was a clinical trial from Sheffield Hospital. When he was assessed for being involved in it, he underwent a liver enzyme test and they said his liver levels were the highest they had ever seen. The doctor said that he should not worry about this and he could still go onto the study. I believe they may have been Mike Makris. This was a very difficult time for Bruce as he struggled with his emotions. He also had worse flu-like symptoms which got so much worse around this time.
38. Bruce was trying to work and do things around this time. Bruce was trying to get back into work. He had worked in social work for a time in Scunthorpe. I do not recall if this was fixed term but this did not last for a substantial amount of time. I recall that he took his home treatment into work and was told he could only inject himself in the toilet. In 1995 he tried to go back to college to be a social worker but he only managed to cope for a year; his health again causing him to 'fail'. Going back to college was all about him improving his chances of getting into a better working environment. It may have been around this time that we decided that we had to go to Relate for counselling together. We were just trying to survive. Bruce was sent to a community psychiatric nurse

who did the usual thing we expected from new health professionals who met him for the first time; she said she had never dealt with anyone like him before. He saw her once and never again. This does not place much trust in anyone.

39. I cannot remember how long Bruce was on Interferon. I recall that the treatment involved injections on alternate days into his stomach. He hated doing it. His treatment was every two days so it never allowed anytime to recover between injections. There was no opportunity to perk up. We now believe that this dosage he was on was too much because I believe this treatment was a trial. The symptoms Bruce experienced were flu-like in nature, and we were aware that this was what would be coming with treatment. We were, however, still surprised with how bad the symptoms were. You just sort of clutch at straws and we hoped it would be worth it in the end. In terms of the likelihood of his treatment being successful, I am not sure what we were told at the start but we and his doctors must have thought that he had a decent chance. I remember that his liver enzymes came down while he was on treatment. The symptoms did not abate. When Bruce stopped the treatment we were happy and hopeful. Within a few months it became apparent the symptoms were not simply going to stop once treatment was over. Before this became apparent we had started to plan and to hope again. I got pregnant in that time but it was almost immediately obvious that Bruce's health was not better.

40. When Bruce was on the Interferon treatment, he was flat-out. This put a huge strain on our relationship. I believe we went to Relate counselling for the first time after his Interferon. According to the doctors, Bruce was cured after his Interferon treatment. This treatment was in 1995 and lasted for several months. I think at the time we were just trying to put one foot in front of the other. We just tried to keep going. They said that that was the end of it. I remember going to see a junior doctor who started giving advice about hepatitis C that we had not been given before, as far as I am aware. He gave us advice about

like things about safe sex to reduce the risk of infecting me. There was a six year gap between the children. This is when Bruce started to get involved with campaigning and fighting for a public Inquiry etc.

41. Around the time that Bruce started campaigning I remember seeing a beautiful picture in a Yorkshire Post of him and our daughter Katie in a beautiful dress. Bruce was doing TV and radio interviews. I recall the reporters coming in to see him. Bruce is not the type of person to sit back and take his situation, especially when there is someone who is at fault.

42. We lived in Redbourne from 1994 until 2001.

43. Having Robbie was a definite choice and this was on the basis of Bruce having been told that he was clear of hepatitis C after having his Interferon treatment. It felt like his life was back on track. This would have been in 1996. My pregnancy with Robbie was awful and there was a threat of miscarriage throughout. As soon as I was pregnant, Bruce's health deteriorated. I believe he was on benefits at that time as well. This meant that after Robbie was born I had to go back to work as soon as my maternity pay was stopped. This would have not even been four months after Robbie was born I went back to full-time work. My intention would have been to take full maternity leave, as far as I would have been allowed. We had to hire a childminder when Katie was young and I never intended to have to have child care like that because as I have said, we had always intended to split parental duties and work.

44. I recall that Rob had ear infections in his early years and had trouble sleeping for the first four years of his life. Bruce would sleep on the settee downstairs since I had work. Bruce could not cope all the time with full-time parenting. I remember that a charity called Home Start would send someone to take Robbie out for a couple of hours but it was

not enough so we did end up needing childcare. This ending up being four days a week. Financially it was a challenge. Bruce was on benefits after he had to quit his social work course. It was only after my cancer diagnosis, which I will go on to discuss, that we managed to pay off loans and credit card debt. I remember that the government brought in three hours of nursery care, but because Rob was born in the May this meant we had to wait until the following January to take a advantage of this.

45. The symptoms that Bruce had after Robert was born were similar to before. Rob was hard-work, he was not the sort of baby that would be sleepy. At this time Bruce's hip was also deteriorating and he required it to be replaced in 1998/1999. I believe that the year 1998 is more likely. Bruce's hip required replacement because of haemarthrosis meaning that blood would collect around his joints and would cause them to deteriorate. Bruce's surgery was not without incident and he ended up walking with a stick after for a time. I remember at one time the doctor was talking to me and saying things about Bruce that were quite horrible. I do not remember the name of this doctor but I believe it was at Hallamshire Hospital in Sheffield. I do not believe this doctor realised that I was Bruce's wife, as I was in my physio uniform at the time. This was an orthopaedic surgeon. Bruce had gone in positive, trying to show how well he was doing, walking with only one stick instead of two. When Bruce went off to a side room, the surgeon sort of threw his arms up in the air and his pen down. It was a display that I would describe as him going "what the hell". I can't remember specifically what he said, but I felt the need to tell him that Bruce was trying his best. This led to further mistrust in doctors and led to Bruce's mood deteriorating. He did not get dressed for months after his replacement. I remember there was one point where Bruce went home, locked the doors and he fell asleep and the children and I were locked out. I remember screaming to try and get him to wake up. My neighbour took us in.

46. At one point we ended up separating in the year 2000. I moved out with the children. I could not cope. I believe that may have been the wake-up call Bruce needed. I moved into a rental house and Bruce initially stayed in the house that was part bought/ part rent. We got back together and put the house on the market. This was a conscious decision as we were paying for the likes of counselling and I had been off work sick. We made a decision to move to rented accommodation because we thought we would be able to claim housing benefit. We were concerned about the pressures of having a mortgage to pay. It took many months to sell the house and all the while we waited to sell, we were paying for two properties. We lost a considerable amount of money because of this. We chose to sell our part buy house because I thought rented housing was a safer option. I was concerned that Bruce would become unwell and I might have to give up work. Things were very unstable.
47. It was not so much of a love/hate situation; it was the situation that was just so difficult then. We had to think of our state of mind at the time. I remember being on antidepressants in 1999 and that did often require counselling. I was struggling at work and Bruce was struggling with caring for the children on his own while I worked, along with his own mental health issues. I couldn't cope with it all, as well as having to take care of my own mental health. Bruce would spend all day in bed. At one point I was suicidal. I remember going to the funeral of a long term physiotherapy patient and I drove to a river and contemplated driving into it. I rang Bruce while I looked at the water and he told me to come home. That was the nearest I ever came to suicide. This may have been the point where I was put on antidepressants or new medication. This was the point I went off of work. Bruce was particularly unwell at this time. When I moved out, when we separated, I built up credit card debt through furnishing the place I moved into. We were just trying to get out of the situation we were put in.

48. We moved to just north of Fortrose in the north of Scotland sometime after 2001. I remember watching stuff about CJD on the news. Bruce wrote a letter to the Haemophilia Society and the then health minister asking if he should be worried about vCJD. Their reply at that point was that the media were just scaremongering. We were shortly after sent the vCJD notification letter I referred to above, proving us right to have been worried.
49. In terms of the treatments for hepatitis C, he had interferon in the 1990s and was offered a new treatment that he declined called Harvoni recently. Places like Japan stopped using it because of increased risk of cancers etc. After our experience of vCJD etc, Bruce researches all treatments and is reluctant to take anything "risky". I am not aware of any treatments beyond Bruce being on Interferon. Because he was on the clinical trial of Interferon, Bruce was given toxic levels of Interferon which explains the side-effects that he suffered at the time and beyond the treatment. These are described above.
50. In terms of how Bruce copes with his condition, when we met, he worked hard and had ambition but very quickly he became sick because of his hepatitis C. I believe that he would have been very much more active without it. We used to climb hills together, but over time he has not able been to do that. Now he can very easily exhaust himself. That has been the case for some time. He can do very few physical tasks, leaving these to be done by myself or the children.
51. Mentally, I would say that fatigue has been quite difficult on Bruce and he has very short fuse. He has never physically harmed me or the children but he does have a very short fuse and does struggle to have empathy. I do not believe he can go more than half an hour without discussing the campaign and every conversation is about the campaign that he is involved with.

52.

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I believe that the campaign has been toxic and damaging. Every bit of him has gone into it. It comes before me, the kids, the house, everything. I understand how important it is to him though. If we did not think it was important, he would be on his own by now. I do hope that he can move on at the end of the campaign and everything else that has gone into this. It has been his every waking thought for the last 25 years. At the beginning of 2018, we went to Fuerteventura on holiday and I begged him not take his phone but he would not leave it behind. This is because this phone is used to communicate with other people involved in the campaign. In the end he did take it and this was an extension of the being at home in the sun, although actually I wouldn't say it was that sunny.

53.

I believe Bruce uses the campaigners as a bit of a coping mechanism. The campaigning has given him a purpose but it is not a good coping strategy. Over the years he has met so many people through this who have now passed away. Bruce knows so many widows because of his campaigning. Bruce has said he would not let it go until he could help those widows. I have often seen that he has given more time to the families of others who have been infected than perhaps sometimes to his own. I try my best to understand everything as I know it is so important to him, but it does occasionally cause friction.

54.

In terms of how Bruce coped physically, I would say that symptoms did not stop after the Interferon treatment. He is still vomiting and there was a period where he had to go on high calorie drinks due to his inability to eat. Even now, Bruce really suffers from the cold and feels the cold. He has a condition called peripheral neuropathy, where his hand does not work quite normally, it's almost like nettle stings or throbbing. This also applies to his feet as well. About four years ago, we moved our bedroom down stairs because of this condition and the resulting falls on the stairs he had had. On one occasion you could see blood through

his socks because he'd fallen down the stairs. It was just after this I was diagnosed with breast cancer in November 2014 . Bruce has continuing headaches and his eyes can go cloudy when he is in different lights. He has problems with his balance and has lumps in his legs that may be due to his hepatitis C.

55. Bruce has lost lots of teeth because of his immune system being poor. He hardly has any back teeth left on one side. He does not sleep well and he does have to beg for sleeping pills from the doctor.
56. In terms of his dental treatment, due to Hepatitis C and vCJD, he does have his treatment in hospital and they have tools that are only for him to prevent the spread of infection.
57. He can't have a gastroscopy because of the vCJD risk. This relates to his oesophagus and he used to get an endoscopy before, but now he has to take a pill camera. At some point, they did stop using pill cameras but there was no alternative that has been offered. He would often have pain in his throat caused by an oesophageal ulcer.
58. In terms of any issues Bruce has had with accessing medical care, I would say that whenever his own consultant is not available, it is a waste of time for him. Bruce doesn't trust other doctors and even if he does try, they don't seem to understand how to deal with him. He is treated at Raigmore Hospital now and his consultant is Joanne Craig. Last time we needed urgent medical advice his own haematologist was not available and the duty doctor wanted to admit him just for a CT scan. Bruce has huge anxiety issues with hospitals so admission should be only as a last resort.
59. I do not know if Bruce has been formally diagnosed, but I do feel that he does have some form of post-traumatic stress disorder and does panic when he is in hospitals. Bruce struggled to come to hospital when

I was in receiving treatment for breast cancer. He would try his best to be there for all my appointments.

60. Bruce had a bladder bleed last year and they sort of fuffed about in the ward and he ended up being discharged after having the minimum treatment he could. There was a lot of messing about. We were quicker spending 30 minutes to drive home and do home treatment than wait for his factor IX treatment on the ward.
61. It would have to be life-threatening for Bruce to go into hospital again.
62. About the social life, I would say that Bruce does not have one. He used to have a season ticket for Inverness Caledonian Thistle football, but due to his inability to cope with the cold outside, he has not been to go. He hasn't had a season ticket now for a few years and he had a couple of friends he would meet there. Bruce does not really mix with people anymore beyond the campaign.
63. I think Bruce struggles with the initial part of the conversation when meeting new people when they ask what he does for work. Bruce does have a couple of old friends from when he was younger. Other than those friends, I'd say that Bruce's friends are all through campaigning and he spends all day on Twitter and Facebook, and researching articles on the internet. At times it has been good that he has the support network of other people that are there to support him, but he is constantly asked for advice and help by other "victims", which can cause disruption and distress.
64. He could be having a good day and then someone else will contact him from this group having a bad day, which does impact his own day – spoiling his mood and causing upset.
65. In terms of the impact on our family life, it was never my intention to work full-time. I also felt I was never good enough at my job. I was

pushed into a job that I was not comfortable with the responsibility of when I was doing physiotherapy. I had wanted to be in a staff physiotherapist position job where I could do my hours and go home to be with my family, but instead I ended up having to be in a position with more responsibility. I wanted to have a good work like balance. Instead I had to try and make myself feel that I was good enough for the position I was in, along with working extra hours where we were always understaffed. I had hoped to be able to go home and be with my kids and have ponies. I had no option to quit or go to a lower paid position because we couldn't afford the alternative. I got ponies after my cancer treatment but my health is not so good now. We never had family holidays. Once we moved up to just north of Fortrose, we spent our holidays visiting my family but we would generally leave Bruce at home. My father and Bruce have had screaming fights in the past so they do not get along. My family struggle to understand why I have not left Bruce. I believe that my family just does not understand hepatitis C and implications of it. Bruce's own sister won't speak to him. He does not have any sort of family get-togethers.

66. When I had cancer, Bruce was very good the first few days and then he seemed to get very depressed. I recall that when I was first receiving treatment for the cancer, I had surgery on 4th December 2014 and by 10th December, Bruce had to go to the Scottish Parliament for a recital of his play Factor IX. I ended up getting an infection and going back into hospital. It was very lonely sometimes during treatment. I recall that after one particularly painful treatment I was in agony and he said something like this is the sort of pain he has every day and he could do nothing to help me. He left me crying at that time. It was a little bit like he was minimising what I was going through at the time. As I have said Bruce does not have an awful lot of empathy. However, I would say that most of the time when I was having chemotherapy, I was still fitter than Bruce was.

67. Our daughter Katie has had to deal with so much. I'd say the impact on her has been worse than the likes of Rob and myself, as I explain below. Bruce does not have a lot of understanding or at least if he does, it does not come across all time.
68. Our household roles stayed the same during cancer treatment. As soon as I was back home, I was back to doing a lot of general looking after the house and things.
69. I got my first pony two years ago and the second one a year later. I got these once I recovered from my cancer treatment. It is an escape from what goes on with the campaigning, although really I had wanted ponies my whole life but because of our situation I was not able to have them. Chemotherapy left me with arthritis and peripheral neuropathy and that does flair up.
70. If feel that my ponies are a therapy from everything and it's also good to have the horsey community. This has opened up my life to having new friends and it has been life changing. I'm often so busy I have to schedule in lunch with Bruce and it can be a struggle.
71. Our daughter Catriona is a very gentle soul who holds everything in. Sometimes I believe she has difficulty expressing herself. Bruce has very much a 'get on with it' attitude and this has caused issues. It was very confusing when he has been angry one minute and then fine, especially when she is like the way she is. I remember Catriona went to the childhood development team at Fortrose Academy when she was a teenager, after she ran away from home when she was 15 or 16 but this was only for a day. The police were called and it was very hard on all the family. Catriona was also seen at the Shenvall Centre at Raigmore Hospital.
72. When Catriona went to university, she went to Heriot Watt in Edinburgh. She lost her grandfather at the end of her first year and that spiralled

her mood down. She ended up admitting herself to a psychiatric hospital in Edinburgh. I believe she may have been self-harming at that time as well. She transferred to Inverness on her 21st birthday and we collected her for a couple of hours. I think that made Bruce realise how difficult it was for her. He tried to be supportive but I'm not sure how effective this was. When Catriona was assessed by a consultant, Dr Sundana, he said that while Bruce was campaigning, Catriona would not get better. I believe he may have also said something about Bruce never winning his campaign and how I had to choose between my husband and his campaigning and helping Katie. After this, I spoke with Katie and Bruce and Katie could see that that could not happen; I believe that that Doctor was arrogant and ill-informed. I considered complaining about him but felt that this would not help my daughter. We decided that we were completely not going to listen to another thing that that man said.

73. I believe the second time that Katie was admitted to psychiatric care was after she and Bruce had had a fight. This would have been around her 21st birthday in 2012. I think she realised quite quickly that she did not need to be there and that was the start of Katie generally getting better. Katie got a little job at a beach cafe and that really helped get her confidence backup. Katie had studied 'A' Level drama before and there was a drama course at the University of Highlands and Islands that Katie ended up going to after having had to drop out of her course at Heriot Watt. She moved out while she was studying in Inverness and this did help improve her relationship with her Dad. Bruce does feel that she is possibly failing to thrive and he is worried at the lack of her career advancing. I believe that Bruce being a stay at home as we had planned Dad might have meant a better relationship between him and Catriona but often I feel that as the mum, I am the go-between and I have to keep the peace between the two of them.

74. As far as Rob is concerned, I would say that he struggled when he was young, especially with him having multiple infections and Bruce

struggled to deal with him. Rob was dyspraxic so he was quite clumsy. He was also dyslexic. I believe Bruce could recognise this because he was also dyslexic. Their relationship can be difficult and they have had real screaming episodes. At the age Rob is now, he has started standing up for himself and really found his voice. I am worried that now he maybe has huge anger issues. His bedroom had to be plastered because he kept smashing walls and doors and other of his belongings. It is hard for me to figure out how to unpick that kind of behaviour. One of the issues I think he has is that he was never able to play football with Bruce and never did what other children's fathers did. Bruce was always on the computer or phone campaigning or speaking with other 'victims'.

75. In terms of the children's school performance, I would say that Katie was very academic and Rob not so much. Rob always needed a bit more of a push to do anything. I think there is still frustration that Rob hasn't done anything to advance himself. Bruce has never completed any course he undertook, but neither has Rob, but I feel that there has been no empathy for Rob and Bruce.
76. I recall when the children were younger, Katie once said that Santa was definitely real because there's no way that we as her parents could have afforded the presents that they had. The kids would quite happily say now that they did not ever do without; though I know we were not able to given them what others had. We have never taken them abroad on holiday or even had real holidays.
77. Going back to Rob's academic performance, I would say that he struggled in school, he was good at maths but his dyslexia did affect his abilities in English. He is not one to ask for help. At one stage he did go off and study forestry for 2 years. He was not able to continue with his studies because he could not cope with the written work or theory.

78. I think the whole family life has been toxic at times. I would often work long hours and I would not be as available to the children as I would have liked. With Bruce, it's been almost like having three children at times. I felt that I had to work to provide for our family – I had no choice, and would sometimes go to work knowing Bruce was unwell and worry about him struggling at home.
79. I believe campaigning has been as toxic as any physical symptom. I think Bruce knows that the campaigning has been harmful. After the Penrose Inquiry, I remember that Bruce went to the Scottish parliament and I had just had chemotherapy. The First Minister, Nicola Sturgeon, and then health secretary Shona Robison had spoken about the payment scheme they wanted to develop. They said that Bruce should be part of the team to work this out and I think that added some extra pressure. I think it was all quite difficult because Bruce hoped that the Penrose Inquiry would put an end to all this but working out the payment scheme meant many more years of campaigning and hard work for Bruce. The Penrose report was so poor that it also meant Bruce would have to continue fighting for justice.
80. Thanks to my cancer treatment I am able to talk to someone at Maggie's, a charity, when I am struggling. I feel that we are living in a house that has always been a compromise, in a situation which has always felt like a compromise.

Section 6. Treatment/Care/Support

81. Over the years, Bruce has had counselling several times with the likes of a community psychiatric nurse and he has tried to access psychological services in Inverness. Bruce accessed this through his GP. The counselling I have mentioned with Relate in Scunthorpe was privately paid for. Often they'll say things like how they've never dealt with someone like him before. When they say things like this, Bruce

has no faith in them. Bruce has no tolerance when someone says they've never dealt with someone like him before and they may not know how to deal with him. I believe Bruce may have been contacted by a psychologist attached to the Inquiry; it's one of the few times that Bruce has felt willing to take part. I believe this was just someone for him to talk to or vent to.

Section 7. Financial Assistance

82. In terms of financial assistance, I believe that we could not get anything from the Caxton Fund because of my wages and that ruled us out from receiving any money. With the Skipton Fund we started on first level and I believe it was in lump sums. I do not remember the dates that we received these but I believe at first we received £20,000 and then a further £25,000. At one point I believe that we have got £14,000 after a professor in Edinburgh diagnosed fibrosis/cirrhosis.
83. Now, I think that we are receiving money through the new Scottish scheme. I think we will be receiving £27,000 split into 12 monthly payments. Since my cancer treatment I have been unable to work or earn, so what we will now be getting from the new scheme is what we would have been earning if it was just my wages coming in.
84. We have put off things, like a mortgage, for years because Bruce has never been able to get life insurance. Even holiday insurance costs an awful lot. If the funding had been brought in 23 years ago, then it would have made a huge difference to our lives and that is very frustrating.

Section 8. Other Issues

85. I think it has been a compromise between the campaign being toxic and the fact that if Bruce did not take part in the campaign then who would

do it. He feels a sense of responsibility. To an extent, I understand that. I have had to give up my own anonymity. Due to my health I did not take part in TV interviews or have photos with the campaigners as I was worried about my patients seeing me in any publicity given I was still working as physiotherapist.

86. I had always known that Bruce might die from his infections for the last 20+ years. He is extremely upset every time someone else dies. Age 54 is the average age that other haemophiliacs who have been infected passed away. I believe this means that Bruce is hyperaware of his own mortality. It feels like we live on a knife edge; forced to live for today but planning for a future that he might not have.

Statement of Truth

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

Signed

GRO-C

Dated

1/5/2019.