

Witness Name: Richard Titheridge
Statement No.: WITN025201
Exhibits: WITN0252002 - 20
Dated: 27 November 2018

INFECTED BLOOD INQUIRY

30 NOV 2018

FIRST WRITTEN STATEMENT OF RICHARD RAYMOND TITHERIDGE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4th October 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Richard Raymond Titheridge, will say as follows: -

Introduction

1. My name is Richard Raymond Titheridge. My date of birth and address are known to the Inquiry. I am a widower with two children and I am retired. I intend to speak about my late wife. In particular, the nature of her illness, how the illness affected her and us, the treatment received and the impact it had on her and our lives together.

How Affected

2. I believe my wife, Patricia Titheridge (nee MacLachlan), was infected with HIV through blood transfusions given at St Mary's Hospital, Paddington in 1984 and 1985 during surgeries for ulcerative colitis and septicaemia.

Background

- 2.1. I met Patricia in 1978. She was working at the Sheraton Hotel Heathrow as a telephonist and I was working in Surrey. We met through a mutual friend. We married in 1980 and lived in Surrey.
- 2.2. In 1982 Patricia was pregnant with our eldest daughter. Up until that point she was fit and healthy, but during that pregnancy she developed ulcerative colitis. At the time, the consultant said that the ulcerative colitis might be related to pregnancy, and that if she had another pregnancy the ulcerative colitis might go away by itself. Our eldest daughter was born naturally.

- 2.3. In 1984 Patricia was pregnant with our second daughter. Unfortunately the ulcerative colitis got worse, not better. She was admitted to East Surrey Hospital at 24 weeks pregnant as she was struggling. She was given drugs to treat the ulcerative colitis but she kept being sick, so she was then given steroids to try and keep it under control. She was in hospital for maybe 10 days to a fortnight. She had developed pre-eclampsia and doctors thought there was no chance of the baby being born alive at that early a stage.
- 2.4. Patricia hung on for as long as she could to try and improve the baby's chances of survival. At approximately 28 weeks Patricia was rushed to St Mary's Hospital in Paddington for an emergency Caesarean section. She was specifically taken to St Mary's as that was the only hospital with a special baby care unit available on that day and our daughter needed a special baby care space as she was premature; in the end she was born weighing 2lbs.
- 2.5. When they performed the Caesarean section on Patricia the surgeon looked at her bowel. Initially they thought it was alright, but it wasn't; they did an x-ray of her bowel during the Caesarean section and performed a total colectomy within 24 hours as her bowel was paper-thin and had to be removed. She was the first ever patient to have a Caesarean section and a total colectomy at the same time.
- 2.6. When Patricia was recovering in hospital after the surgeries, she began complaining about feeling sore inside and having a burning sensation. One night I got a call from the hospital telling me to rush up there as she had developed septicaemia and they were performing an emergency surgery to clear it out. They said Patricia was at death's door. This was probably two to three weeks after the Caesarean section and colectomy.
- 2.7. I believe that they must have given her transfusions at the colectomy and at the septicaemia operation. I have since obtained letters dated 2003 in which a doctor states that he had accessed some of Patricia's medical records on microfiche and she had two transfusions with a total of nine units of blood, although one unit was returned unused. These letters are exhibited as **WITN0252002-3** and **WITN0252005**. Patricia never had any other transfusions and she never took intravenous drugs or had any tattoos.
- 2.8. Patricia was in hospital for about two months overall following the Caesarean section, which was on 5th October 1984. She came home just before Christmas. When she came home, the prognosis was good. The consultant was proud of the job he had done; he even got her to appear in an auditorium before medical students to say what a difference the colectomy had made to her life, because she was such a special case as she was the first one to have the colectomy with a Caesarean section. After about six or seven months, Patricia started to pick up and live a fairly normal life, she was fine.

- 2.9. About a year after the surgeries, she had to go back and have the final bit of the operation. This was approximately in 1985.
- 2.10. After the operations we seemed to have some kind of quality of life, although Patricia was never the same. It was a big operation to have in her 20s and she didn't like wearing a colostomy bag and the associated things with it. But we carried on and we moved to Scotland to build our empire; in 1990 we moved just north of Perth.
- 2.11. Patricia was fine for a good while, right up until 2000 when she started to develop symptoms including a butterfly rash on her face, aches and pains, rheumatoid problems and falling asleep at work. I know it was around 2000 as we had just moved into our current house. She deteriorated between 2000 and 2002. By Christmas of 2002 she was really poorly, she was in a very bad way; she couldn't get off the couch and she was delusional, she was talking to herself but it didn't make any sense. The GP came round on Boxing Day 2002 and she was taken to Ninewells Hospital straight away in an ambulance.
- 2.12. At first the doctors at the hospital treated her with massive doses of antibiotics. I don't think they knew what they were treating her for; I think they presumed it was some kind of infection that would respond. She did partially respond to the antibiotics at first, but then she slipped back again. After about 10 days they asked me if they could test her for HIV. They asked me because she wasn't mentally in a place where she could answer, she didn't have capacity. I said I had no objection to her getting an HIV test, nothing had come of anything beforehand.
- 2.13. A day or so later they called me and asked me to come in. I was taken to a private room. My two daughters were also there, they were aged about 18 and 20 at the time. The consultant was very good, I must say. He told me that unfortunately my wife was HIV positive and that it had affected her brain. The consultant put Patricia on some medications and said me and my daughters had to get tested for HIV. We were all shocked.
- 2.14. I got tested the next day and fortunately I was clear. GRO-C

GRO-C

GRO-C

- 2.15. I wasn't given much information about what HIV involved when I was told that Patricia was HIV positive. There didn't seem to be much about what HIV involved except what we saw in the news. I knew there would be stigma attached and that people would look at her differently if they knew she was HIV positive, but otherwise I learned as I went along. I would have liked to have been given more initial information. This was the early 2000s; I'm not a computer person so I didn't find out information using the internet, I got information from news articles, the consultant at Ninewells, and the community nurse.
- 2.16. Whilst the initial information we were given about HIV could have been better, the support and information we got afterwards was good. The consultant at Ninewells Hospital was quite good in explaining to me the drugs that were available now compared to past drugs, and Ninewells Hospital had a special area for communicable diseases.
- 2.17. Although I was told about her diagnosis, Patricia wasn't told that she was HIV positive for the first 18 months. She was diagnosed in January 2003 and I didn't tell her what was wrong with her until April 2004. The consultant and her GP agreed with me that it would have been cruel to tell her what was wrong with her because she couldn't remember anything, and my daughters agreed with this too. It would have been like telling her she was HIV positive everyday, she wasn't capable of understanding it.
- 2.18. She was in an extremely poor mental state. Her memory was shocking, she cried all the time, the HIV must have affected the emotional part of her brain and the doctors couldn't stop her crying. I had to be with her all the time. I tried to work, fortunately I was self-employed, but eventually I just couldn't work and I had to give it up. I spent most of 2003 sitting on the couch with my wife because she wanted me with her and she would be hysterical without me. She wouldn't want anybody else.
- 2.19. In April 2004 I told her she was HIV positive. I invited her family and best friend round, they were all aware of her HIV status already as I had told them. We told her together. When I told her she was HIV positive, she said, "I knew". She was devastated.

- 2.20. I hadn't wanted to tell her at that point but her psychiatrists had been putting me under pressure to tell her for about five months. We eventually had a meeting with the GP, community nurse and the psychiatrist to discuss it. My daughter was there too. They all said it was the law in Scotland, a patient had to know what was wrong with them, although the GP and consultant agreed with me that she shouldn't be told. The doctors said the law was different in England, so I considered moving down to England with her so that I wouldn't have to tell her. But in the end, after all the pressure from her psychiatrists, I decided to tell her. It was the right decision to tell her in the end, though I think I was right to put it off whilst she couldn't understand. By the time we told her, she had picked up a bit and she could understand more.

Other Infections

3. I am not aware of Patricia contracting any other infections from infected blood besides HIV.

Consent

4. As far as I am aware, my wife was not tested for HIV before January 2003. It took the doctors so long to find out what was wrong with her that I don't think that they could have already known she was HIV positive – if they had known that already then they might have come to the right diagnosis earlier on and helped her.
- 4.1. However, I suspect that she may well have been tested for HIV in the years following the transfusions once it became known that HIV was transmissible through blood transfusions.

Impact

5. Patricia didn't experience any symptoms or have any signs that anything was wrong up until about 1999. She was fine up until then, besides having had the colectomy, which caused the odd blockage associated with the operation. However, around 1985 we started seeing things in the papers or on the news about an AIDS scandal, and we saw something mentioning St Mary's Hospital. We had to go back to the consultant for a routine appointment, so Patricia asked the consultant then whether there was any problem or whether there could be any chance that she might have AIDS. He was very dismissive. He waved his hand and said "no chance". It was like he was suggesting it was ridiculous. But Patricia was always worried that there might be a problem.

- 5.1. Patricia first began to show symptoms in about 1999. She developed a butterfly rash on her face, was very tired, had aches and pains, and rheumatoid problems, all sorts of things. They thought it was celiac disease, then rheumatoid problems, then Crohn's disease again, they kept going round and round in circles. She just got worse and worse and worse. Eventually she got made redundant for medical reasons, she was falling asleep at work and they had to let her go. She just couldn't work, so she stopped working and she rested, but she kept getting more and more ill.
- 5.2. During this time we saw doctors to try and find out what was wrong; we went everywhere we could, we even went to see a gastroenterologist privately. We told all the doctors that Patricia had had blood transfusions during an operation at St Mary's Hospital, but nobody seemed to put the pieces together. My wife always thought that there might be a problem to do with the blood transfusions, but she was frightened, and every time a doctor reassured her that they were looking into something it moved things away from the blood transfusions.
- 5.3. Patricia's condition deteriorated between 2000 and 2002. Most of the time she was asleep on the couch, she would talk to herself when she was awake, you knew something serious was wrong. I wondered if she had a brain tumour or something like that. By Christmas of 2002 she was in a very bad way. The GP came round on Boxing Day 2002 and she was rushed to Ninewells Hospital by ambulance, and 10 days later they tested her for HIV and it came back positive.
- 5.4. When she was first diagnosed Patricia was in a very poor physical state. One day in January 2003 we went in to the hospital and the consultant told us she had multifocal leukoencephalopathy, inflammation in all different areas of the brain. It seemed that the HIV had bypassed everywhere else and gone straight to her brain. He said her condition couldn't be treated and she had 6-12 months to live. Patricia responded well to treatment though and eventually the doctors decided she must have had a lesser version of it, encephalitis.
- 5.5. Once the HIV drugs kicked in and started to work, her blood counts got to normal or thereabouts, and she improved. The aches and pains and rheumatoid problems cleared up quite nicely. She could walk around fine; she used to walk on the golf course with her friend, and she did fine for a good while. Her brain was damaged by this time though, and she still had mental problems.

- 5.6. The HIV affected her brain in all kinds of ways. It affected her hormones and mood; for the next 2-3 years after she was first diagnosed she cried constantly, she was on several drugs to try and help with the crying and mood, but they didn't work and she would get hysterical unless I was with her. She wouldn't want anyone else around her, only me, and I had to stop working to be with her all the time.
- 5.7. In approx. 2005 she had to be admitted to a psychiatric hospital in Perth, the Murray Royal. She took an overdose of diazepam, which only made her sleep but it alerted them to the fact that she needed help. She was at the Murray Royal for about six weeks. They weaned her off a lot of the drugs she was on – she had been on diazepam, lorazepam, morphine sulphate and sleeping pills, and none of the drugs were having an effect, they just built up drug after drug and she continue taking them all. So they controlled the drugs she took, and they did some really good work with her, and when she came out she was a lot better.
- 5.8. Some things would make her cry just like that, but with other things, she seemed to manage quite well for a reasonable period of time. I had to become a sort of amateur psychologist; when I talked to her about things I would build her up and try and keep her mood up. I got quite successful at it and we managed to keep going, get away on some holidays, and she was much better up until 2011 when she started to get ill.
- 5.9. Another way in which the HIV affected her brain was that she would hear voices in her head. If I was talking to her, that would echo in her head over and over. So in order to get rid of that effect, we had music playing in the house 24/7 because if music was playing then she would concentrate on that. Music would play in every room in the house, all day and all night long, sometimes the same records on repeat. We didn't watch TV for several years because we had the music playing all day long.
- 5.10. It also seemed like the brain damage had affected her logic, you couldn't reason with her. You would explain something one day and the next day it would be gone. For example, she had this thing about going charity shopping; she would buy clothes virtually every single day, then wear them once and put them in the cupboard, then go and buy more the next day. She did that for years.
- 5.11. She was like a child in some ways. I'd say, "Well why don't we just get you something nice once per month? You don't need to go charity shopping day in day out." And she would agree, and then it would be forgotten and back to the same old routine. You never knew what went on in her head because you couldn't rationalise it in any way. She wasn't the woman I married, she was a completely different person.

- 5.12. Once we told Patricia that she was HIV positive in April 2004, she was distraught, but it also answered a lot of questions for her. She had been so ill for such a long time and hadn't known what was the matter for her. By that point she was better able to understand what was going on, as up until that point she hadn't been well enough to understand, and she improved for a good four to five years after that.
- 5.13. We managed to go on some holidays, things like that. She came to terms with the situation as much as you can. She used to write anonymous articles about her experience; one of these was an article for Grazia magazine which I have exhibited as **WITN0252006-9**. She wrote other articles, including one for a Scottish newspaper, and she published a memoir which I have exhibited as **WITN0252020**. She also got involved in campaigning; she was good friends with a campaigner in Glasgow who was also infected. They did things to campaign for justice – one day we went to Scottish Parliament with him and the MP for Glasgow and obtained what documents we could about infected blood under the 30-year-rule.
- 5.14. In 2010 and 2011, Patricia got a lot thinner but she still wasn't doing too badly. I could start to see the effects of her illness though. Then in August 2012 she twisted her ankle one day and her condition went downhill from there. At first she couldn't walk because she had twisted her ankle, but then, because her head was in a different place, she wouldn't try to walk and she ended up in a wheelchair. She became immobile. She had been smoking and drinking for years but it increased considerably around this time. I would tell her it wasn't doing her any good, she would kill herself if she kept going like that, but you couldn't reason with her. I tried to get her to change her ways. She smoked and drank herself to death; I think she had just had enough. By that point, it had been 10 years since she had been rushed to Ninewells Hospital and diagnosed with HIV. She had lost a good friend of hers who was also infected and her sister had died. I think she just lost the will; she had run out of steam and she didn't want to continue. She went downhill and she died in December 2012 of pneumonia – that is what is recorded on her death certificate.
- 5.15. Once Patricia was diagnosed with HIV in January 2003 she was put on antiviral drugs; I can't remember the name of the first combination. She did not react well to it though – she experienced bad side effects. She would get major nightmares and she wouldn't know what was happening; she wouldn't know if it was day or night. On several occasions she would wake me up at 1am and suggest we go for a walk. I would tell her it was night-time and she would say it wasn't, so we would walk the streets at 2am and she would swear it was daytime.

- 5.16. These drugs also affected her sleep; she would be awake for a whole week with no sleep, and so I would be awake too for a week. She would occasionally doze off next to me on the couch, so I would doze off too, and then she would wake up and it would go on again. Another example of how the drugs affected her is that she would forget where our bed was. Our bedroom was on the ground floor and she would keep going upstairs to go to bed because she couldn't remember where it was. It was a very odd period.
- 5.17. She wasn't on these drugs for too long, they changed her onto a second combination as the first combination wasn't working. They put her on combivir and nevirapine, and it was different. She became as normal as she was ever going to be again. She was on these drugs until she died.
- 5.18. Once Patricia was diagnosed there were no difficulties in accessing treatment for her HIV. I do not think that there were any treatments which she should have been offered, but was not offered. The consultant at Ninewells was good in explaining the drugs available and how they differed to the old drugs.
- 5.19. Aside from the physical and mental effects the HIV had on her, it impacted her life in other ways. She was frightened of people knowing that she was HIV positive because we lived in a small town and she was afraid people would look at her differently. She wanted to keep her diagnosis within the people she knew and trusted. When she found out that she had HIV she was very worried about the possibility that the girls might have become infected; kids can cut themselves easily and things like that. Because of this she wanted our younger daughter to get tested, although our younger daughter didn't want to.
- 5.20. We were lucky to be living around the people who were around us. They were educated people and good friends; they never made her HIV an issue. Our family never made it an issue.
- 5.21. There was an incident where Patricia's chiropodist refused to treat her once she found out that she was HIV positive. The chiropodist used to come round to do Patricia's feet every so often. I hadn't told her that Patricia was HIV positive as she didn't need to know. She read one of Patricia's anonymous articles and put two and two together, and she asked me about it and said I should have told her. That was the last time she did Patricia's feet.

- 5.22. That resulted in another incident as the podiatrist was friendly with someone who was a bit of a gossip. After the incident with the podiatrist, the podiatrist's friend ended up putting something on a website about Patricia being ill and not having long to live. I don't know what kind of website, I didn't use a computer in those days. Somebody else saw it and told me what she had written on this website - when I found out, I went mad and had words with the woman who had posted it, I made her take it down.
- 5.23. The main impact for Patricia was the fact that she knew herself about the HIV – she didn't let it affect the way she was with her friends and her friends didn't let it affect the way they were with her. With the damage to her brain she had become a new person; everyone just accepted that and did what they could to make it better.
- 5.24. We were quite resilient really, outside of that it didn't affect us too much. I tried to keep it quiet as I didn't know how it would affect my work, and particularly so when living in a small town. Patricia started writing anonymous articles about her experience and published a memoir which covered her life before and after her diagnosis, which kept her occupied. She got involved with campaigning.
- 5.25. It had a big impact on my daughters. My daughters were aged 20 and 18 when Patricia was rushed to hospital after Christmas 2002 and subsequently diagnosed with HIV. The girls were with me when I was told that Patricia had tested positive for HIV. They were very shocked, as was I.
- 5.26. My eldest daughter was probably the most practical of all of us, she is very matter of fact. She was at university studying science when Patricia was getting ill, so she was away from it all, but I think it hit her how ill Patricia was as we didn't see a great deal of her, just holidays. She had come home from university for Christmas in 2002 and I think she was quite shocked to see what Patricia was like then.

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GRO-C	Patricia's illness affected her though,	GRO-C
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She got through it and she graduated from university and she now works in the pharmaceutical industry. She was very good with Patricia, she used to take her out here, there and everywhere.

- 5.27. My youngest daughter is more emotional. She was very affected by Patricia's illness. She was living at home when Patricia was getting ill. She was studying at college in Dundee, so she was back at nights and weekends. She was the one who suffered the most as she saw it all the way through; she saw Patricia deteriorate and she saw the problems afterwards. [GRO-C]
[GRO-C]
[GRO-C] she would be in a state for a good while; and she would be crying a lot. It was only when she got out and went to university in Dundee that she started to do a bit better, as she was away from it all. I was glad that she had managed to get out of the house and carry on.
- 5.28. All the way through I tried to protect my daughters from the problems going on because I wanted them to live their lives, to enjoy university and live a fairly normal life. I took most of it on myself so as to protect them – they had been affected enough already. I don't think Patricia's illness affected their education; they both got their degrees.
- 5.29. My wife's illness had a huge impact on me. When we were initially told Patricia had 6-12 months to live after she had been diagnosed with HIV, it was a bit of a double whammy. I was numb. I went to the off-licence and got a bottle of whiskey and got drunk. That was how I reacted when I got the news. We were shocked. And then after that, it was just make the most of the next year, as that was what we thought she had left. When it turned out she didn't have that death sentence of 6-12 months, we carried on.
- 5.30. Seeing her through the illness and everything like that, from the point she got ill to her death in 2012 – it had a huge impact on me. Her illness was the toughest period in my life by a mile. During those first few years after the diagnosis, she would cry all the time. I would be sat up night after night with her crying, day after day with her crying. When she was on the first lot of antivirals, it was walking up and down the road.
- 5.31. I used to have my own business as a self-employed painter and decorator. I had built my business in Scotland up from nothing. When Patricia came home from hospital in 2003 she would cry all the time and she wanted me with her, no one else. Because I was self-employed it meant I could spend time with her, but then I couldn't work properly. I would try to go out to work to earn some money as we didn't have any money coming in, but my wife would get hysterical and after 10 minutes at work I would have to go home to placate her. I kept trying to work but it ruined my business. I spent virtually all of 2003 sitting on the couch with Patricia. After that year, my wife's best friend came to live with us for two years. [GRO-C]
[GRO-C] She helped out as best she could, but my wife still wanted me with her all the time.

- 5.32. Because the HIV had caused Patricia to hear voices in her head, we had music playing nonstop for years in every room of the house so that she could concentrate on the music and voices wouldn't echo. It would be on in the sitting room, the bedroom, all night long. I got out of touch with everything; I didn't watch Panorama, the news, things like that. Although the music wasn't loud, music 24 hours a day was too much for me. We ended up sleeping in separate bedrooms because she had music all night long and I needed peace, so I slept upstairs. We set up a bell system towards the end; she would ring a bell if she needed to get up in the night, and I would come down and help her to the toilet. That would happen 3 or 4 times a night; sleep was a premium.
- 5.33. It all took a mental toll on me. In 2010 I took an overdose. I got a bottle of whiskey and sleeping pills and I ended up in hospital. That was something I wish I hadn't done, but sometimes you get to the stage where you think you can't do it anymore. I had spent ten years looking after my wife. I used to have brown hair; now it's grey. I ended up seeing a psychologist, which was really good; it helped me to cope a bit better. It's hard to put into words the effect it has on you. I didn't know if I was coming or going; the way the illness affected her, I was done for. When she died, I felt I was a spent force.

Treatment/Care/Support

6. Once Patricia was diagnosed the treatment she received was very good. The big problem was that our local GPs didn't know how to deal with it. My GP, who has now retired, said that my wife was the most difficult and complicated case he had ever come across because they never knew what they could do for her. This was the problem.
- 6.1. I think the psychiatrists also treated her well, but they are different to the other side of things. I think they get to the point and can be quite harsh, but that's what they had to do. I didn't take well to them because of the pressure they put on me to tell Patricia about her diagnosis.
- 6.2. After I was told that she was HIV positive, I had a meeting with her GP and consultant, and we decided it was best that she didn't know about her diagnosis because she wasn't able to take it in.
- 6.3. In 2004 the psychiatrists were putting pressure on me to tell her about her diagnosis. They said it was the law in Scotland that a patient had to know their diagnosis and it was black and white, no shades of grey. At this point I didn't think she had the capacity to understand it; I still thought she wasn't able to take the information in and nor did the consultant or GP. They and my daughters were on board with me.

- 6.4. They put pressure on me for about five months, saying I had to tell her. She was at home by this point, but we had appointments with them, and they would regularly mention it. One time we had a meeting at the GP surgery; it was me, my daughter, the community nurse, the GP and my wife's consultant, and then the psychiatrist. Everyone put their case forward and the psychiatrist just said she had to be told.
- 6.5. I finally told her in April 2004. She had improved by then and was in a slightly better frame of mind. If I had told her when the psychiatrists wanted me to, I am not sure she would have survived. I don't think she would have been able to mentally take it in. The psychiatrists might have been right on the legal side of things, but I think I was right to put off telling her until I did. They gave me no choice but to tell her, as they said they would withdraw treatment.
- 6.6. In terms of myself and my daughters, we have all been treated pretty well.

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- 6.7. I was prescribed antidepressants but I never took them. They weren't going to change my situation. They said it could take the edge off, but I still had to deal with what was in front of me. I wasn't experiencing anxiety, I was struggling to cope. I didn't think they would help, so I never took them and I'm glad I didn't. I dealt with it the way I saw it. I didn't accept any help that other people offered me; I thought I could deal with it myself, but I was wrong.
- 6.8. I don't remember being offered any counselling as such when my wife was diagnosed. The community nurse from Ninewells was helpful. I didn't see a psychologist until after my attempted overdose – it was only then that they got involved. When I took the overdose I was in hospital for just a few hours; they took me in and checked me out, and apparently I hadn't taken enough to do any major damage. We ended up with a bit more help after that; I started to get respite vouchers from Perth and Kinross. My wife got an allowance for someone to come in 15 hours a week as a personal assistant, where a woman would come in and take her out for coffee or lunch. I was able to save my respite vouchers up so that I could take a full day. But there was no way I could take a full day, so it was pointless. The only time I had a break was when my daughter would take my wife for a weekend. My daughter lived in London then, so we would put my wife on a flight at Dundee and my daughter would pick her up at the airport in London. That was 2-3 times a year.

- 6.9. The worst thing about getting respite, when my daughter would take my wife for a weekend, was that we would have all the logistics of organising it beforehand and getting her there on the Friday, and then I would just put the TV on and try to get a bit of normality. Then on the Saturday I would play a game of golf and Saturday night I would be preparing to have her back on Sunday; so with even a whole weekend of respite I would only get one free day, and half the time I wouldn't know what to do with myself because I was used to dealing with her.

Financial Assistance

7. About a year and a bit after my wife was diagnosed, our doctor told us about the Eileen Trust. The community nurse and the consultant did the application for us, they handled the paperwork. About 15 months later the Eileen Trust gave us a one-off compensation payment of £80,000: £40,000 for me, £40,000 for my wife and about £500 for the girls. In order to get the money I had to sign a handwritten note saying that I wouldn't take any legal action. At the time we really needed the money – we were in financial trouble as we had a mortgage to pay and I wasn't working, we had bills, and I borrowed money off family and friends to get by. The money from the Eileen Trust meant we could pay off the money I had borrowed, pay off the mortgage and set our daughter up in London. We were also paying university fees too.
- 7.1. The Eileen Trust gave us monthly payments. At first it was £350 per month and I think they also gave my youngest daughter a grant for university. The monthly payment then went up to £650 per month, which was a big help, and it stayed around that figure. But we could also apply for grants if we needed it; they would help with paying for a break, or if something needed doing to the house. I was never comfortable with it because I had never lived like that before – I had never claimed anything from anybody. I felt uncomfortable at being put into that position. But we needed the money; it was the only source of income we got, besides my wife's benefits. She received Disability Living Allowance and something else, which I can't remember; we received two payments and a Motability car. When she died, the Eileen Trust also helped with funeral costs.
- 7.2. After the Archer Inquiry, my wife's monthly payment doubled from £650 to £1200. When she died I received an allowance from the Eileen Trust because I was a dependant.
- 7.3. I feel we were ushered into this Trust, forced to sign this letter before they would pay any compensation, and then they stretched it out long enough so that you would be desperate to get the money. It took 15 months before we received any money because they were trying to trace the blood to prove that she was infected. In the end, they couldn't trace all the blood, so they did it on the law of probability.

- 7.4. Recently all the Trusts were condensed into one scheme. Under the Eileen Trust I was receiving £650 per month, which was a big help. I retired last year but I did a little bit of work to try and help my daughter pay for her wedding. I paid in about £6,000 or £7,000 for her wedding. Because of this, I had to have a review done with the agency that deal with the Trust payments now, and they have reduced my monthly payment down to £83.00 because it is index-linked. I have applied to be re-means tested because I am now retired, and I am waiting to find out if I get another review.
- 7.5. When the Eileen Trust existed, I felt that the trustees were hand picked to do a job and that job was to keep us happy and stop us pursuing legal action. But they did look after us; the Eileen Trust was very good – we had weekends away etc. There aren't many of the Eileen Trust left; they cared about us and looked after us. With the Eileen Trust I knew everyone, it was like a little family. When the Trust disbanded, there was a little money left and they spread it amongst the registrants.
- 7.6. The Eileen Trust was essentially a charity, although they call it a Trust. It's a charity, and I'd rather not have charity, it doesn't sit well with me. If they had originally paid proper compensation in the beginning you wouldn't have to have the Trusts and the inquiries, it would have saved money and dealt with the problem properly.
- 7.7. I could try to work but it's pointless – in order to earn the money I used to get, I would have to work a lot more, and I'm too old for that. I have tendonitis in both elbows, housemaid's knee etc.

Other Issues

8. The one thing that has really bothered me is the lack of legal action. Around about 2007 my wife and I were going to seek legal action; we met with Irwin Mitchell in Sheffield and they seemed quite keen at first. And then a week or so later they rang us and said that we wouldn't get legal aid and we could lose the house. That put us off legal action. We were trying to raise medical negligence. My wife was keen on that; she felt pretty aggrieved.
- 8.1. I look back and wonder why there has never been a legal case that got through in Britain. I would like to know why. In other countries there was legal action, but not in Britain. Were the big solicitors' firms dissuaded from taking on cases? I know that there were no legal cases heard for transfusions in the Eileen Trust.
- 8.2. My wife's medical records for England, including her surgeries at St Mary's Hospital, Paddington, have disappeared. I have her medical records from Scotland but no backdated reference. There is very little information from England.

- 8.3. In 2003 our doctor tried to access her medical records for England and found some scarce documents on microfiche. This is referenced in the letters exhibited as **WITN0252002-3** and **WITN0252005**. In or around 2007 I tried to access the medical records from St Mary's. I wrote to ask for them. After I hadn't heard anything in a long time, I phoned up to ask about them and I was told that her records had been destroyed in a sewage leak. They said the sewage leak happened before 2003.
- 8.4. I then phoned them up again and said that I thought they were mistaken, because our doctor accessed my wife's medical records in 2003 on microfiche. They then told me that the records no longer existed because they routinely destroy medical records after 15 years, so there was no chance of getting medical records.
- 8.5. This didn't sound right to me. They had changed their story. And why would you destroy medical records in someone's lifetime? Having the records disappear cost my wife – if someone had looked back at the medical notes and seen the timing of the transfusion, someone might have realised that she was infected earlier on.
- 8.6. My MP, Pete Wishart, also tried to access her medical records. He was very good, he tried and tried, and he was as helpful as he could be, but he couldn't access them. That was in 2007/8.
- 8.7. Moreover, my wife's surgery in 1984 was a unique case. She was the first person to have a Caesarean section and total colectomy at the same time. Her consultant had even asked her to speak to his students in an auditorium because she was such an important case. Why would you destroy those records?
- 8.8. It's easy to go down the route of conspiracy theories but the whole situation leads to it. As much as I would like to think there isn't a cover up, I think one actually happened.
- 8.9. My wife had to have the operations and she had to have blood transfusions, there's no question about that. But when a test for HIV was available, when they knew about the problem of blood-borne viruses in the 70s and the danger of importing blood, when they knew there was a test available but wouldn't pay for it – it has cost a lot of people their lives. You don't know how many people have been left out there infected, who have been tested for HIV but were never told of their status, and who have gone on to infect people.

Exhibits

9. The investigators have taken a series of 18 photographs, which are exhibited as follows below. I have also provided the investigators with a book.

WITN0252002-3	A two-page letter from Dr P E Hewitt to Dr A J France dated 6 October 2003 about my wife's medical records
WITN0252004	A letter from Dr P E Hewitt to Dr A J France dated 12 June 2007 about my wife's medical records
WITN0252005	A letter from Dr P E Hewitt to Dr A J France dated 26 June 2003 about my wife's medical records
WITN0252006-9	An article written by my wife anonymously and published in Grazia magazine dated 8 May 2006
WITN0252010-11	A transcript of "Reporting Scotland" which aired on BBC TV Scotland on 23 May 1991
WITN0252012	A letter from David B McIntosh of SNBTS to J T McDonald at the CSA dated 17 December 1990 re: HIV patients infected by transfusion
WITN0252013	A letter from David B McIntosh of SNBTS to J T McDonald at the CSA dated 27 May 1991 re: HIV patients infected by transfusion
WITN0252014	A document titled "History of Factor VIII leaflets", date unknown
WITN0252015-17	A document titled "Summary of SNBTS response to HIV contamination of PFC coagulation factors" by Dr R J Perry dated 11 March 1988
WITN0252018	A letter from Dr R J Perry to David McIntosh dated 15 April 1991 re: FVIII, 1982 - present
WITN0252019	A fax covering sheet from the Scottish Office dated 11 June 1991
WITN0252020	A copy of "Cheating the Reaper", a book written by my wife about her life.

Statement of Truth

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

Signed

GRO-C

Dated

28/11/18