Witness Name: T M D Warwick
Statement No: WITN 3623001
Exhibits: 0
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF TINA MARY DOUGLAS WARWICK

I, Tina Mary Douglas Warwick, will say as follows: -

Section 1. Introduction

1. My full name is Tina Mary Douglas Warwick. I was born on GRO-C GRO-C 1957. I live at GRO-C GRO-C North Yorkshire, GRO-C with my husband Richard.

2. I am self employed. I have a clock and barometer repair shop in Scarborough.

3. I make this statement as an affected person. My husband Richard is a Haemophiliac and has been infected with the Human Immunodeficiency Virus (HIV), Hepatitis C (HCV) and Hepatitis B (HBV) through contaminated blood products. He has provided a witness statement to the Inquiry (WITN1592001).

Section2. How infected

4. I met Richard on Boxing Day night in 1987. I already knew what Haemophilia was. My father's colleague and best friend was a haemophiliac. Sadly, he died from an internal haemorrhage in the early 1960s. Coincidentally, he was the maternal uncle of the older boy that Richard travelled to and from Lord Mayor Treloar College with from 1976. Richard had attended Lord Mayor Treloar College from 1976 to 1982.

5. I had an overall understanding of what being a haemophiliac meant but had no experience or knowledge of the current methods of treatment at the time we met. I knew that Richard had some mobility problems, especially because of damage to his left knee. He explained that he had severe Haemophilia A, having less than 1% clotting factor naturally in his blood and had been able to give himself Factor VIII injections for some years.

6. Eventually I learned how to prepare his injections for him. I noted that, from time to time, the branding on his home treatment boxes changed though I can't remember the names. We collected Factor VIII from our local Scarborough Hospital Path Lab once or twice a month depending on his bleeding episodes.

7. Richard also suffered from grand mal epilepsy. He told me that it had developed suddenly in his mid-teens around the time that he was learning to drive. It had a devastating effect on his life. At first the seizures were at night but eventually they could happen anytime especially if he was tired or in a lot of pain from his joints or a bleed. The combination of epilepsy with haemophilia made him a danger to himself and others in the workplace.

8. Richard believes he was most probably infected with HIV and Hepatitis C whilst at Treloar College. Using his medical notes he has been able to identify batch numbers that he was given for treatment that were known to be contaminated.

9. Richard's medical record show that he was diagnosed with HTLV3 (HIV) virus on 27th November 1985 but he was not told until three years later.

10. He was officially diagnosed with Hepatitis C in March 1993.

Section 3: Other infections

11. Richard received letters in October 2004 and in 2009 stating that he may have been infected with vCJD as a result of being given infected blood products and was "at risk" from a particular batch which doctors had identified as possibly being contaminated with vCJD.

Section 4: Consent

12. It is apparent from records of tests and correspondence between his various Doctors and treatment centres that Richard was tested for viruses many times over the years at different treatment centres and without his knowledge or consent. He was not informed that the blood taken from him was being tested for HIV, HBV or HCV. He believes that some tests were done for research purposes at Treloar College

Section 5: Impact

13. As our relationship became more serious Richard confided in me that there was concern that some Haemophiliacs had been infected with the AIDS Virus. There were some in America but cases in Canada and the UK were being reported. He said that he thought he was OK but the advice from the Haemophilia Society was that barrier forms of contraception and safe sex practices should be followed. There was no advice with regard to stopping Factor VIII treatment and reverting to Cryoprecipitate.

14. I had no knowledge of any earlier forms of treatment. Richard had told me about how his parents would have to prepare and administer his

treatment when he was young, before he went away to Treloar College. The reports and news stories were alarming and concerning of course, but more because of the potential stigma of belonging to a 'suspect' group. We were in blissful ignorance of the full impact it could have.

15. However I remember specifically the outrage when news reports appeared about Haemophiliacs being denied entry to the United States. We were not planning any trips there but it was a shock to find that we were in an excluded group. Then there was the realisation that as a blood donor I could not continue to donate once I was in a relationship with a Haemophiliac. I wrote to the Blood Transfusion service explaining and resigning and received a very nice letter back, thanking me for my donations and agreeing that I could not give blood in future.

16. We continued to grow closer throughout the spring and summer of 1988. Richard still had his bedsit but we were practically living together at my parent's house. My parents and sister liked Richard very much. I met his parents and sister and we all got on extremely well. It became apparent just how intelligent Richard is. His innate understanding and extensive knowledge of electronics, computers and radio had manifested at a very early age, guided and encouraged by his father. He wrote programmes for computer games in his teens and has always spent a great deal of his time repairing and building electronic equipment. It is his way of coping with pain and discomfort. He can also look at anything mechanical and understand how it works. This delighted my father, who was a watch and clockmaker and Richard became very interested in this field and would go to my father's shop and find some project to undertake to make himself useful. This eventually resulted in him making me a counter top tester that I still use as it is better than anything else I could buy to test watch batteries and diagnose faults. Then he designed and built me a radio controlled wall clock as my time base. It is the most accurate clock in a very wide area as Richard's updates itself once a minute unlike most commercially available radio controlled clocks that only update once a day.

17. He has also designed and built a speaker system that uses plasma to relay the sound. He put a demo video on YouTube and it was seen by the producers of a Spanish TV kids science programme. They asked if they could feature it on their show and it ended up travelling to Spain and back. Richard spent many hours translating the instructions into Spanish! In the past couple of decades he has turned his talents to sourcing and archiving TV and radio media for Tainted Blood, encompassing 40 years of historical information.

18. I wonder what he could have accomplished if he had not suffered this awful fate? If he could have had the resources of a large research and development department behind him instead of just being on his own in the spare bedroom. If he had not had to cope with the increasing fatigue, the "brain fog" or the "wall with the occasional bricks missing" (as he described it) caused by the viruses and the medication given for them then I feel he could have gone from computer programming to developing Apps for instance. As with my battery tester and clock he is able to observe and pin-point a need for a particular piece of equipment and if one isn't available, he will design and build it. I could list pages and pages of projects he has made. One time he built a pocket inverter supply to test mains-powered equipment. He made a bat detector which we took to an event in Dalby Forest. It outperformed the Ranger's professional detectors and we were able to log more species because of its wider range of frequencies. It became rather embarrassing as a crowd of fascinated children followed Richard round the field like a sort of Pied Piper of Hamelin! This is also how he copes mentally with the stress of living with these viruses. We are all in admiration at how he refuses to indulge in self pity and loses himself in concentration on his latest self-appointed task.

19. When I first met Richard, he was attending a haemophilia clinic at St. James Hospital, Leeds. His consultant was Dr GRO-D who he saw about twice a year. He obtained his Factor VIII from Scarborough Hospital Path Lab department run by Dr Balfour.

20. In November 1988 he went to his GP Dr James Adamson. I cannot remember the circumstances which led to this but there was an increasing climate of concern amongst Haemophiliacs. This was pre-internet and social media and Richard wasn't in touch with any of his friends from Lord Mayor Treloar College at the time. The only information we had was from the media and via The Haemophilia Society. I can't remember if he was called in for a test or requested one or if his doctor asked him to make an appointment but I do remember that he went on his own and I waited at home, in my parents house until he came back.

21. He walked in and asked to talk to me upstairs in our room and I knew what it meant. Dr Adamson had told him that he was HIV positive. We were obviously very upset and frightened for the future. At that time the outlook was not good for those diagnosed with HIV but because Richard seemed asymptomatic I don't think that the full seriousness of the situation really hit me at the time. It was more of a drip, drip of the implications of Richard's status over the following weeks and months. Initially I was worried that I may have also contracted the virus but that soon passed. I never really considered that I could have, we had always been careful and maybe also it was part of the unwillingness to engage fully with what this meant. I can't honestly remember if I then went on to have a test at my own doctor's or not. This seems strange in hindsight but the only time I can remember being specifically told that I was HIV negative some months later.

22. Richard went to see Dr GRO-D quite soon after. I can't remember if I went to Leeds with Richard on that occasion. If I did I did not go into the room for the consultation, Richard told me what had been said afterwards. He was very angry as he felt that Dr GRO-D was quite offhand and dismissive towards him and had said, "You knew that you were positive". Richard said that he knew no such thing and had never been told. He left the consultation and refused to go back to see Dr GRO-D again. He was very upset.

23. In the following spring of 1989 we had an 'accident' with contraception and I became pregnant. I knew very quickly that I was pregnant and did a home test just to confirm my suspicions. Richard and I watched the 'positive'

line appear and then I went to see my GP. This all passed in rather a blur, we were still in a form of shock from Richard's diagnosis and we had a sort of unwillingness to look too far into the future. I don't have many clear recollections of that time. I think I have blotted it out. I tried to just forget about it afterwards and having to think about it for this process has not been easy.

24. I cannot recall much about the discussions prior to the termination of my pregnancy. Richard remembers that we were strongly advised not to have the baby. Certainly I knew that we couldn't have coped with a baby on top of what we were already coming to terms with. There was the risk that I could have been infected, that the child would be born HIV positive and even if this were not the case it was an unspoken thought that it was likely that I would be on my own before too long. At the time there seemed to be no choice, it was simply a matter of coping with what had to be done and getting on with it. At that time, testing for HIV wasn't quite as straightforward as it would become. Because it was possible to have a false negative result it was recommended that testing should be repeated after 3 months. This obviously had serious implications in terms of a pregnancy.

25. We didn't tell anyone else about this. We didn't want to upset our parents any more when they were already so worried about us. Luckily my termination was scheduled for early summer and my parents were away on holiday at just the right time. I was about 16 weeks pregnant then. Richard came with me to the hospital and stayed as long as he could. He was back early the following morning and once all was completed and all checks and tests were done we went home and simply tried to forget. It was especially hard to do it without the help and support of my mother. When we told our families some years later they were very shocked and upset.

26. My HIV test came back negative. This of course means that the baby would in all likelihood have been OK too. This is painful to think about, but of course our decision wasn't only to do with HIV status. We were a traumatised, confused and frightened couple and not in any state to become parents. Having said that, over the years the feeling of loss and regret has

become stronger and stronger. Some time later we heard about 'sperm washing' and I did inquire about this during a consultation at the HIV Clinic, at Monkgate, York. I asked if we were suitable candidates but the general mood seemed to be that they weren't keen to seriously discuss it as a possibility. I think this was mainly due to my age. I think I was probably in my early 40's by this time. I allowed the matter to drop. Again, with hindsight, I should have pushed more, but by then we were also aware of Richard's Hepatitis C infection and there were several changes to his HIV medication that were very difficult for him because of the side effects. We had enough to think about and cope with.

27. I am very bitter that we were unable to have children. As time has passed and I have reached an age when it was no longer even a consideration it has become a black cloud of sadness that is always in the back of my mind. I have seen friends have their babies and watched them grow and seen the happiness a full family life can bring. It is like a club that we cannot be members of; forever excluded. This is made worse because there was nothing wrong in that department with either of us. I always feel inferior to other women because of our childless status, somehow a "lesser" person. It is rarely appropriate to explain why and therefore people make judgments and I feel that I appear unworthy of their attention and inclusion in their society.

28. I am extremely angry that decisions made by others, seemingly with money, dismissive complacency and self interest at the forefront, have robbed us of the chance of a family. The one source of comfort is that my niece has 4 wonderful children who are extremely important to me and are the nearest I can have to grandchildren. I have never had the chance to hold my own baby. If I had thought clearly and hard heartedly about it all those years ago, in order to have children I would have had to leave the man I loved just when he needed me most; that was never going to be a possibility.

29. In late 1989 Richard and I moved into a rented flat; it was near my parents and his doctor's surgery. Richard was not on any form of medication for HIV at that time but in March 1991 he was at last given AZT. At that time

it was the only treatment available as far as we were aware. He was also prescribed Septrin, an antibiotic that he took for many years to prevent a specific lung infection that HIV sufferers often fell prey to.

30. We had to collect his AZT medication from St Jame's Hospital, Leeds. Richard had not seen Dr GRO-D and was unwilling to have him as his treating consultant anymore; there had been a complete breakdown of his trust.

31. We had to go downstairs into what seemed to be the bowels of the building to collect AZT from the pharmacy. It was a very frightening experience. The mood was one of gloom and it was very depressing and oppressive. Richard's dose of AZT was 1000mg a day. It was horrible for him. He suffered side affects of nausea and sickness. He was often dizzy and felt weak and had little appetite. We struggled on and had decided that it was time we should marry. If the future was uncertain at least it was a sort of security and was something happy and positive for a change.

32. We married in July 1991. We had a lovely day and went on a short Mediterranean cruise for our honeymoon. I thought that Richard could benefit from some warmth and sunshine and a cruise was ideal as he could enjoy the scenery whilst relaxing. Richard is 6ft 2" but at the time of our wedding he only weighed 9 stone. He was very thin and gaunt. He coped very well with the travelling and maintaining his medication and his Factor VIII treatment when necessary but he doesn't really remember much from that time. He doesn't recall the excursions we took. I remember that he did relax a lot on deck and found that he enjoyed eating a lot of fruit, especially the water melon that was always available. It was refreshing and didn't upset his stomach.

33. After marrying we decided that we should try to buy our own house. A joint mortgage was out of the question; Richard was uninsurable so it would have to be a mortgage based on my salary alone. Luckily as we live in the north of England we managed to find a small bungalow that was affordable in a quiet location a few miles from Scarborough. It gave Richard the peace

and quiet he needed to do what he wanted and the space, having a large garden, to explore his interests and projects and ignore his increasing symptoms. Also there was only one set of neighbours and we could keep a low profile. We were beginning to hear stories about abuse, intimidation and hostility that some Haemophiliacs were encountering. As we couldn't take out any of the usual mortgage protections it had to be at a level that I could manage if I were to be left on my own. We moved in May 1992 and have lived here ever since.

34. By this time Richard was seeing Dr Derek Johnstone at Scarborough Hospital. He had set up an HIV clinic and also acted as Richard's haemophilia centre since Richard would not see Dr GRO-D any more. He had a good rapport with Dr Johnstone and it was he who told us, in May 1993, that there was another virus that had appeared amongst haemophiliacs, especially those infected with HIV. He wanted to test Richard for it. The test was positive. There was no treatment for what was eventually called Hepatitis C and we accepted this new virus with, essentially, a shrug. Richard knew that he had had Hepatitis B whilst at College and had cleared it naturally so initially we weren't too worried about it. There was little to no discussion about what symptoms Hepatitis C could cause. We just carried on as usual.

35. Soon after this Scarborough Hospital then took on a specialist consultant to take over the treatment of HIV positive patients. Dr Ian Fairly was a GUM doctor. This new clinic was based at Scarborough Hospital, a clinic on Northway and also at The Monkgate Health Centre in York.

36. We quickly established a rapport with Dr Fairly, his Specialist Nurse Practitioner Fiona Wallace and all his clinic staff. I found it very distressing to have to attend what was essentially a GUM Clinic especially when our appointment was at the Northway Clinic, which was well known in Scarborough for being 'that' kind of clinic and was very public. I didn't want to be seen going into and coming out of the premises. Dr Fairly understood and we had our subsequent appointments at the hospital where it was a lot less obvious that it was a GUM clinic and quite soon after we decided to attend

his clinic in York. This was a bit further for me to drive but a lot more anonymous.

37. Dr Fairly and his team were keen to utilise new drugs that were being developed and move Richard from AZT which was being recognised as a drug that caused at least as many problems as it addressed and it wasn't doing a very good job of keeping infected patients alive anyway. We attended this clinic every few months and our lives began to be dominated by Richard's blood test results; specifically the T4 cell count, white blood cells that fight infection and also the viral load, the amount of virus present in his blood. At first his T4 count was falling from in the thousands for a 'normal' level to around just 30 at the lowest. The viral load testing came a little later and over the years these tests have become more sophisticated. What would have been 'undetectable' as a viral load in the 1990s and early 2000s when testing began would now show an exact figure. So 'undetectable' today is truly a negligible amount in the blood. I cannot remember the starting figures for Richard's tests, bearing in mind he had been infected for over 20 years by this time, but basically his T4 count was low and dropping and Viral Load was high. He was very thin and gaunt, exhausted with a poor appetite. He often suffered with stomach and bowel upsets and bouts of dizziness. His epilepsy was always a background worry and also caused problems for Dr Fairly in case the Phenytoin reacted with the new HIV treatments. He spent a long time in conversation with the pharmacy trying to weigh up the latest information of side effects being reported. All these drugs were so new, some even on a named patient basis, that every patient essentially was a test case. He also routinely informed our local GP surgery and Dr Howard. They all tried to ensure that blood test results were shared so didn't need to be replicated by all three specialists. Later when Richard was referred to St. Jame’s, Leeds for Hepatitis C treatment all information was shared from them too.

38. The consensus was that the virus was better being attacked by a multiple drug regime. Dr Fairly prescribed various tablets over the next few years and monitored T4 and viral load results. Some caused dreadful problems and had to be changed. Richard went through hell; he suffered any

and every form of side effect that you could think of. Some that stick most in the memory were that his legs and feet swelled to massive proportions. They were red hot to the touch, which he could hardly bear; they itched and burned. He couldn't even bear a thin cotton sheet to touch them, so sleep was virtually impossible which meant that he was at severe risk of a seizure through exhaustion. I could not leave him and watched him like a hawk.

39. Thankfully the drug that had caused it, Didanosine / DDI, was stopped quickly and changed for something else. His scalp was often excruciatingly tender and felt as if it has been scalded. He came out in rashes, especially on his lower legs and feet. He developed double vision which in turn caused nausea and was awful for him. Driving in the car was a horrible experience and he was trapped at home unless travel was essential. I can put the beginning of Richard's trouble with his feet at this time. He had a lot of arthritic pain from his ankles but began to develop peripheral neuropathy in his lower legs and feet which has got worse over the years. HIV and HCV are now known to cause this nerve damage. This has compounded Richard's mobility difficulties. Not only are his joints weak and damaged because of the arthritis caused by bleeds but he can't feel his feet properly. This makes his walking risky and even more difficult and unstable. He has an understandable fear of falling. If he was injured and, especially if he was bleeding, he would have to disclose his HIV status to whoever came to his aid. This is a dreadful worry and has led to Richard being uncomfortable in public and in crowds and he prefers to travel in our own car, whenever possible.

40. By the beginning of 2000 Richard's viral load had begun to climb again, he had developed resistance and Dr Fairly, Fiona and their team were keen to change his medication to add in a fourth drug; so called HAART therapy, to overcome this. However, again, after talks with pharmacy specialists the drug had contra-indicated Phenytoin for his epilepsy. There was a careful, lengthy process of withdrawing Phenytoin and then starting another epilepsy drug. The drug Phenytoin prescribed to Richard for his epilepsy had caused swelling and overgrowth of his gums. This meant that he often suffered from painful infections as food would become lodged down in his gums, beyond

the reach of his toothbrush and they would also bleed a lot. He lived for years with the pain and inconvenience of this as well as the unsightliness.

41. The epilepsy drugs had such a detrimental affect on Richard's well being. They caused dizziness, confusion, memory loss and lethargy on top of those symptoms suffered as a result of the viruses.

42. Gabapentin was tried but Richard started to have much more frequent fits. I remember receiving a telephone call at work from his parents one afternoon and having to dash home. He had suddenly gone into a major fit and crashed to the floor. Luckily they had called by to see him. His mother was in tears and his father was in despair at seeing him so physically frail. Not long after Richard phoned me at work and I could tell that he wasn't fully aware of the previous hour or so but he knew he had hurt himself. I shut the shop again and got home as soon as I could.

43. A nightmare scene awaited. There were bloody footprints and hand-prints in every room; Richard was slumped in his office chair holding a bath towel to his head. This towel was clean and cream when I had left that morning and was now completely red with blood. I went towards him and nearly fell as I slipped on the carpet which was soaked with blood around his chair. We learnt that he had fallen into a fit in our tiny bathroom and crashed down against the toilet and sink. A fit means that he would have had involuntary thrashing of his limbs so he was bruised and battered with multiple joint and muscle bleeds. He sustained nasty gashes to his head which had bled profusely. After this stage of a fit Richard comes too a little. He can get up and walk but isn't fully aware of his surroundings and what is happening. This is why the whole house was affected as he stumbled about. Thankfully he had been able to phone me for help and by the time I got home he was almost fully aware and we could prepare some Factor VIII and he injected himself. Then I took him to Scarborough Hospital so his gashes could be stitched and he was checked out for further injuries.

44. It took a long time for Richard to recover from this episode. He had lost a lot of blood but Dr Fairly and his team who were treating him were unwilling to give him any transfusion. At the time I was puzzled as to why

not, still being naïve and unaware of the full facts. I remember they said that it was much better for his body to repair itself rather than intervene. That whole summer Richard was weak and often dizzy and slept a lot but eventually regained some colour and felt better. This was certainly also helped by the withdrawal of Gabapentin. He was prescribed Sodium Valproate which suited him far better. He is still on this and right from the start it has reduced his fits and his gums have improved.

45. Since 2000 Richard has been quite stable on this quadruple therapy, his viral load has remained undetectable and his T4 cell count has remained at a reasonable level, though this is deemed of less importance now that more is known about the virus. There seems to be a rather dangerous general assumption that HIV can now be controlled by 'simply' taking tablets. This is not the easy option; they are very strong drugs and cause their own problems. Richard has had to take anti-diarrhoea tablets daily for most of the past 20+ years. The epilepsy, we now know, is caused by these viruses and as he was undiagnosed and untreated for nearly 20 years there is a lot of damage that is not reversible. There is also still stigma, prejudice and an element of segregation in being HIV positive.

46. Though we are extremely grateful for the care and advice given by Dr Fairly over the years, I did notice that after he had given advice about the drugs he wanted to try, whether on a named patient basis or already available, he always asked Richard if he wanted to go ahead. My cynical side thinks that this is to shift responsibility to the patient in view of these strong, newly tested drugs and their multiple side effects. It seems strange to give extensive clinical information in a professional manner and then finish rather lamely asking the patient if they should go ahead and obtain the drug.

47. Doctor Martin Howard, a haematologist had set up a Haemophilia Clinic in York which we have attended now for a couple of decades at least. Doctor Howard has been very supportive and also ensured that Richard got access to the new form of high purity Factor VIII as soon as York obtained it. He has also helped when we had to apply for PIP for Richard in recent years. His exasperation and disdain for the whole disgraceful process was

evident and he was pleased to give us a signed letter outlining in clinical terms just how badly Richard is affected by his multiple problems; as did Dr. Fairly.

48. One rather shocking incident happened a few years ago when we had a routine appointment at Dr. Howard's Clinic. We were being seen on that occasion by a young female doctor. We had seen her before and she was very pleasant. After the main part of the consultation she leant forward and said very seriously, "Richard, can I ask please, are you still taking drugs?". We both gawped at her, open mouthed. I couldn't believe what I had heard. Richard managed to say, through gritted teeth, "I haven't got these viruses because I am a drug user, I was GIVEN them by the National Health Service!" She was obviously very shocked at this and was extremely embarrassed. She apologised and said, "I am so sorry, that is so sad." Richard snapped that it was more than sad and we left it at that. The appointment ended rather abruptly and we haven't seen her since! Apart from the shock and anger this incident made me very sad. I thought to myself that 'they' had almost won. If a new generation of medical professionals were coming up through the ranks now who had no idea about what had happened, most especially those working in a haemophilia centre, then those who have dismissed us as a nuisance and irrelevance for nearly 40 years had nearly succeeded in sweeping us under the carpet. Perhaps we should have put in a formal complaint but we just wanted to get out of there without losing our tempers and starting to shout.

49. During the 1990s and into the 2000s there wasn't much mention of the Hepatitis C. I think it was in 2003 when Richard was referred to the Hepatology Clinic at St. Jame's in Leeds. Initially they were keen to discover just how damaged his liver was as liver function tests showed his body was dealing with the viruses and the medication quite well. I remember that they admitted him for a liver biopsy they prepped him for surgery and then they had a change of heart. The risks for a Haemophiliac of a biopsy outweighed the need for a look at liver tissue. So we went home. There may have been some sort of scan taken at some point but a specific fibroscan on the liver wasn't available, or at least given to Richard, until some years after.

50. His first treatment for Hepatitis C started in November 2003. This was Pegylated Interferon and Ribavirin. It was as unpleasant as we had been warned it would be. Richard was itchy; rashes appeared. He suffered from the scalded scalp feeling again, headaches and nausea. The injections into his stomach and thighs were very sore and remained red and swollen. He ran out of untouched places to inject so it was even more painful. He was depressed and moody and it was a very difficult time. After 12 weeks there was no effect on the virus so treatment was stopped. Whilst it was a relief for him to get over these physical symptoms, the fact that it was all a waste of time was upsetting.

51. The rest of the decade passed with a growing awareness of just how serious and deadly Hepatitis C was. Richard started to use the internet and especially social media to get into contact with ex pupils of Lord Mayor Treloar College. It was very shocking to find how many had died. We had attended a couple of reunion events and also had made contact with others similarly affected through The Macfarlane Trust. This was set up after the litigation settlement in 1991 when we were in ignorance of further viruses and the knowledge that manufacturers, government and doctors had prior to what was admitted to, when we were offered an all or nothing deal.

52. The Macfarlane Trust had many failings but a very good thing that they did was organise weekends away for affected haemophiliacs. There were men only events and also others for wives and partners. It was a great source of comfort to meet other people in the same boat. Whilst it may seem that the men only version was rather old fashioned and exclusive, I saw how much Richard got out of it and the inclusive events were just as good and as much fun. It was at these weekends that we could attend meetings and compare notes. It was unceasingly obvious just how much we had been lied to, dismissed and misled. There was a growing undercurrent of anger and I had my own 'road to Damascus' moment when I realised that every infected person without fail was beginning to uncover the truth behind their diagnosis; that there was a delay in telling them that they were infected. Freedom of information, increasing availability of records over the internet and especially

the rise of social media sites were all combining to create the opportunity to track down the truths and the lies. Eventually this led to the founding of Tainted Blood and other groups.

53. Richard used his knowledge of computer systems and data management to do a lot of research and also to help others who were not as computer literate. It has been his main task for over a decade and has given him focus and a purpose when things have been very difficult for him.

54. He was called back to St. Jame's for further treatment in 2013. They were having good results with the Pegylated Interferon and Ribavirin adding a third drug Telaprevir. Richard had specific questions based on his own research. Could they say that the optimism they were showing was actually justified when he had been co-infected with Hepatitis C and HIV for more than 30 years? Was it not true that the presence of HIV greatly reduced the likelihood of the treatment having an effect and having had both viruses for so long reduced the effectiveness to little or nothing? That the greatest success was with patients who had recently been infected from transfusions with Hepatitis C only? It became apparent that the team were unwilling to directly answer these points; I feel that they couldn't answer based on their small sample of case results.

55. Richard consented to go ahead and began treatment though with a lot less hope than the first time. It was just as horrible again. He suffered from dreadful side effects until he wanted to scratch and scratch until his skin bled. He was depressed, angry and irritable and life wasn't easy. Just as well that treatment was halted after just 6 weeks in July. The team had seen that the viral load although lower, hadn't been properly suppressed and their growing experience was showing that in these cases it very soon stopped being effective. Treatment was stopped forthwith in order that resistance couldn't develop in case of future courses. This failure, twice over, was very depressing. There was a growing feeling that now that whilst the HIV seemed to be held in check, the Hepatitis C would get him in the end. People we knew were beginning to die of liver cancer by this time.

56. Richard's liver had been coping well and Fibroscans had been stable at around 13 on the scale that they used. However in December 2014 the latest scan gave a reading of mid 20s, his cirrhosis was advanced now and he had begun to feel discomfort from his enlarged liver. At this time we were also hearing about new treatments for Hepatitis C. There were a couple of options but they were only being given to patients at end-stage cirrhosis or even with liver cancer. This was very worrying as we knew Richard's health was deteriorating.

57. Nevertheless the team in Leeds did start to consider Richard for this new treatment and during the summer of 2015 there was a change of policy. Because of its effectiveness it was being rolled out for most qualifying patients as the ultimately cheaper option. Richard began this new Harvoni treatment on 15th August 2015. I noticed a change in the team and the way they gave advice prior to the new treatment. Before there had been an air of gloom and warning, talking about depression and even suicidal thoughts as well as purely physical symptoms. This new course was presented in a much more optimistic way. We were still given emollients and creams for itchy skin relief but the underlying message was that it was all going to be good. After 12 weeks of relatively side effect-free medication Richard cleared the virus.

58. He was checked at 6 months and then again at 12 months. The viral load was undetectable and even more encouragingly, his liver appears to be recovering. Fibroscans have shown that his liver is 'softening' and now the results have fallen from the high just before the 3rd treatment to single figures now. They class this as a cure and we have every reason to hope and believe that this is the case. The discomfort from his swollen liver has diminished and he has found that he has gained some weight. It has been explained that this is probably because his body is now able to process his food intake better. He also suffered from dark black and purple discolouration all over his feet and up his shins. We had always assumed that this was linked to circulation problems but it has largely disappeared since he cleared HCV.

59. After a year Richard was discharged from Leeds and responsibility was given to Dr Charles Millson at his Scarborough Clinic. He is still attending this clinic roughly twice a year to be tested. They offered to discharge Richard completely as his results were so good this summer, but we discussed it and requested to continue with the monitoring. We are still nervous that there may be a small chance that the virus could recur or that Richard is, in any case, at an increased risk of liver cancer.

60. Some damage cannot be undone; the neuropathy hasn't improved and he now suffers from spasms in his legs when he is seated or in bed. This is very painful, disturbs his sleep and his legs spasm past the point which is his normal range of movement. It is excruciating for him and it causes bleeds in his knees and ankles. For years he hasn't been able to stand his feet being touched, even putting his own socks on causes his legs to jerk, but this spasming has appeared in the last decade and has got much worse over the past few years. There doesn't seem to be much treatment at the moment, we haven't even got a proper diagnosis or explanation for it yet. Circulation or it being somehow linked to epilepsy are two avenues of inquiry.

61. Richard is still often very tired and lethargic. His appetite is poor and although he hasn't had an epileptic fit for several years now and has been able to reduce the medication, his short term memory is poor and he can find it difficult to collect his thoughts. His long term memory has a lot of blank areas that he has no recollection of, for instance our honeymoon. He has digestive problems caused by medication and also has to take Loperamide tablets regularly to prevent diarrhoea. His eyesight is still affected; double vision comes and goes and he suffers from headaches. Recently he has begun to experience temporary loss of vision in one or both eyes. This is currently being investigated.

62. The effects of living with the viruses have taken their toll. Richard can be very irritable and angry. He can be extremely unpleasant during these mood swings and later will be very sorry for cruel remarks and impatience. This is not the man I married and I try to understand and be supportive but

sometimes the best thing to do is remove myself and leave him in peace until he feels better.

63. He also feels guilty that he is still here when so many of his peers aren't. His whole outlook on life has been shifted by his experiences and he can be rather callous and seemingly uncaring. This isn't the 'real' Richard and I think it is a form of PTSD, though he isn't the type to want to discuss it by accessing 'talking' therapy.

64. We have always been very private and careful about disclosure around HIV/Hepatitis C. We have been lucky in that we could keep a low profile where we live. For nearly 30 years we have kept our heads below the parapet but it has become necessary in this past decade to add our voices to the fight to be heard. This is quite frightening and overwhelming. We have seen how inaccurate reporting can twist a story and there are those of our small, brave community who have suffered terrible injustices.

Section 6: Treatment/Care/Support

65. Counselling has been made available to both Richard and myself on many occasions but is something neither I nor Richard have wanted to follow up.

Section 7. Financial Assistance

66. I am self employed and run a clock and barometer repair shop in Scarborough. Having such a rare and specialised business has been fortunate over the last 30 plus years as I would have been unable to work the hours that a more 'normal' career would have necessitated and an employer would have had to have been extremely understanding about me taking time off to care for and support Richard.

67. Over the years I have only been able to run my business part time because of Richard's needs and treatments. My income therefore has been

very low and I couldn't afford pension payments over normal national insurance contributions. Richard has never been able to work; his whole life and future career was wiped out by being given these viruses. His potential was great; his sister has had a very successful career, as did his father. They both achieved high status positions in their fields through merit and they would both say that Richard is cleverer than they are and his ability to throw himself into the most complicated projects, as well as saving his sanity for 40 years, would indicate that he could have had excellent employment prospects. He and I have been cheated and robbed of the life we could have had. Many of my friends are now retired from their careers and businesses. I have no such prospects; although not large I need the income that my shop brings.

68. In 1991 Richard received a lump sum payment from the MacFarlane Trust which we put towards our wedding and a deposit on our bungalow in order to have a manageable mortgage. Otherwise we would never have been able to own our own home. He signed the waiver.

69. I received a payment from the MacFarlane Trust in the sum of £2,000, also in 1991. This was a payment made to me directly for the loss of my baby and I, too, had to sign a waiver.

70. I cannot remember the wording of the waiver and I cannot remember the amount that Richard received but I remember attending a meeting with a solicitor in Sheffield and there were a number of us in that meeting. I cannot remember what we were told specifically suffice to say that in order to move forward we were all told to sign the waiver to receive the payments.

71. Richard was given some money monthly from the Macfarlane Trust (MFT). Usually incorrectly reported as compensation, it was nothing of the sort. It was to help with the increased costs of living with the viruses. Extra heating, special foods etc. There were also grants available from the Trust but it was quite demeaning to apply for these. The first time Richard rang them it was to ask for possible help to purchase a replacement car. He was told no very firmly and abruptly. Some years later we did obtain help with the installation of double glazing and a new boiler to help reduce our bills. This

was from the Skipton Fund and we had to fight hard to get it. It was quite a long process and we had to obtain and send quotes and supply receipts. This caused some difficulty as we had to go with the cheapest quote and the company folded immediately afterwards. We had terrible trouble obtaining a receipt for the money we had paid to send it as proof to the fund! It wasn't even for the full amount, we still had to pay out a considerable lump and worried that we would even have to return some if we couldn't get the receipt.

72. After this the Trust seemed to be coming up with various schemes to distribute their remaining funds. It was very confusing; they hired a media marketing company at great expense to send out a questionnaire to recipients. This caused great offence as it asked for very personal and confidential information. The questionnaire was withdrawn and the Trust apologised. Then they decided that staff should literally tour the country, visiting claimants to assess their needs according to their living conditions. Heaven knows what this cost. We had our appointment confirmed; we hoped for help with some carpets and bathroom updates. As the letter said that we could have a medical professional there too to help with the assessment, the specialist Nurse Practitioner from Dr Howard's Clinic offered to come. She gave up her time and cancelled appointments for the whole day just to be there to support us. It was a very demeaning process with a long form for the MFT representative to fill in. It was a very intensive means test and I was embarrassed with the whole process, especially the inconvenience to the Nurse Practitioner. All of this came to nothing. As far as I am aware the whole process was scrapped and no-one got their grants. What a waste of everyone's time and the costs involved.

73. Richard has received his Skipton fund payments as a stage 2 patient. We have used this to pay off our mortgage to help us be more secure. We really need a larger house but we have prioritised security.

Section 8. Other Issues

74. For more than 30 years I have had to stand by and watch my husband go through absolute hell. I have shared every set back, every emotional blow and every disappointment at a failed treatment or bad test result. The despair of feeling helpless and the fear of the future are indescribable. I have been lucky to have the support of my own family although I lost my father 20 years ago and this year, my mother. My parents-in-law are two people who can absolutely understand and share my experiences; I have the utmost admiration for them and am so very grateful for the love and support they have always given.

Anonymity, disclosure and redaction

75. I am not seeking anonymity. I understand this statement will be published and disclosed as part of the Inquiry. I am willing to give oral evidence to the Inquiry.

Statement of Truth

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

GRO-C

Signed ....

Tina Mary Douglas Warwick

23rd October 2019

Dated ....