Witness Name: Joseph Paul Peaty
Statement No: **WITN4607031**
Exhibits: nil
Dated: 13 April 2023

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF JOSEPH PAUL PEATY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 January 2021.

I, Joseph Paul Peaty, will say as follows: -

1. I make this statement in addition to my statement of 8 September 2021 (**WITN4607001**) to cover the time period after I left the Lord Mayor Treloar College in 1984 to my current situation now.

Section 1. Impact on Education and Work

2. Shortly after leaving Treloar's, with the revelation about my HTLV III infection and the knowledge that this would likely progress to AIDS, I found myself reviewing all of my life goals. I was battling an overwhelming depression that I did not want to burden my mother with, so consequently completely alone and lost, without any support. I decided there was no point in applying to university and pursuing the career in computing that I had envisaged beforehand. Prior to my diagnosis, I took a tour of the computer centre at Warwick University and had foreseen the huge technological

advancements in this area. In all honesty, I struggled to find any purpose to live.

3. In the summer of 1984, the news was heavily broadcasting material on AIDS, which had a damaging impact on myself and other haemophiliacs. I had come to the realisation that my life would end prematurely and it was therefore difficult to answer questions about what I was going to do in terms of university and my future career. I had just completed my A level examinations and had decided to put university on hold.

4. After several months, I came to the realisation that I needed to do something to occupy my final days and to avoid dwelling on the inevitable. Realistically the unthinkable could happen, but there was always the possibility that a miracle could happen. I reached the understanding that whilst I could not invest in a long-term career which required study at degree level, I needed a distraction and therefore began exploring more simple goals. I found a couple of job opportunities within the Local Authority Education Department, one of which had a computing element. I successfully applied for a job as a clerical assistant in the Planning and Research Section, taking up my post in January 1985. The role enabled me to have an outlet where I could express myself and ended up being a good distraction from my health as I found the work interesting. Computing was only just beginning to be incorporated into the workplace, spreadsheets were basic, slow and had little function but I was the most technology savvy in the office and used them for statistics. I also created pin maps for population representation to map population growth. This allowed the department to identify baby booms, in order to determine where schools should be located along with their catchment areas.

5. When I initially started working at the Local Authority, a concern was expressed about my haemophilia and how much it would affect my ability to work consistently, however the position was supported by the Manpower Service Commission, who had a mechanism in place to support the employer if I was off work unduly because of my condition. It was fairly

obvious that I had to use a wheelchair from time to time because of the haemophilia, but the infections were kept completely private. In actual fact, I was off work sick far less than expected, but from the employer's perspective, I understand that if an individual was likely to miss a lot of time off work, it would encourage them not to employ them. Nevertheless, I was still viewed as requiring special mechanisms and made to feel that I was at a disadvantage because of my disability, which is why I felt the need to work harder to demonstrate my ability.

6. A year into working at the Local Authority, secretary to the Assistant Director of Education had some time away and I assumed her position for a couple of months. It was quite a responsibility but it was a huge insight. This led to a secondment to the Buildings Maintenance section where I became involved in an IT project regarding building maintenance in schools and ended up in premise support after a reshuffle, where I created an IT system for supplier orders and invoicing. I found the work interesting and had the opportunity to utilise my computing skills.

7. The Local Authority actively encouraged career development with one initiative being day release for university studies. As part of this scheme, I completed an access year at college before starting a university course at Coventry Polytechnic in Business, Law and Economics. I loved reading law and it became another possible career direction, however, the year of part time study took its toll as HIV was starting to take effect. I was so fatigued from work, that I would go home and collapse. I had no reserves of energy to commit to studying and having enjoyed the course, disappointingly I had to cut it short and was unable to complete the degree. It became another development in my career that I was unable to explore, which fed into the constant disappointment that I was not able to fulfil my potential.

8. As schools became independent from local authorities and were given their own budgets, a finance and administration position arose at a large comprehensive school in Coventry. I was successful in the application and remained in the role for some time before leaving to join another secondary

school as an administration assistant. I was naturally embarking on a career pathway in business management and had forged connections with Headteachers over the years to further advance my vocation, but my ill health meant this was not possible.

9. Over the years, I found that I was able to distract myself from my health by immersing myself in work. I was certainly slower because of my condition, memory and fatigue, so I would work longer hours, not caring if they were paid or unpaid, as I never wanted to let anyone down. In time it became more difficult to maintain the facade that I was well and healthy. Where possible, I would blame the haemophilia because that was understood compared to the HTLV III infection. The fact that I was struggling both physically and mentally with a secret condition meant that it was not supported and I could not justify my position.

10. I expect there may have been suspicion because colleagues knew about my haemophilia and associations were being made between haemophilia and AIDS in the news. If the conversation arose, I would brush it off by remarking that I was one of the lucky ones. I did not like lying to people, but the stigma associated with the virus meant that I could not be completely open and there was a lot of uncertainty about disclosing information of this nature – others were so badly discriminated against that they lost their jobs on the spot. I had also heard about fellow Trealor's students that had their home targeted and I did not want to bring this on my parents.

11. It is hard to describe how difficult it was to keep working and remain motivated throughout the persistent fatigue, but I continued to mask my condition and tried to portray myself as someone who was capable and deserved chances to develop. I never wanted my haemophilia or infections to curtail any progress, however, I made it to the final application stages of the Local Authority IT Career Path but stumbled at the last hurdle because of the disabled access. They could not allow me to go up and down the stairs because of the safety risk – whilst this felt discriminatory, it became a reality check.

12. In my final role as an office manager, my health deteriorated further and I started to struggle with a low immune system. I experienced constant fatigue, had episodes of collapsing at work and suffered with horrendous brain fog, which meant that I had to rely more on notes and reminders to myself. My day-to-day responsibilities at work involved maintaining financial systems and assisting in budget management, running the IT system in the office, keeping track of orders and deliveries, whilst managing a team of 4-5 people and reporting back to the admin officer and headteacher. It was a very important, busy role with a lot of pressure and at one point in my career a referral was made to occupational health to ensure that my reasons for being off sick were legitimate.

13. I took time off work for a holiday in 1996 and upon my return to work I became very unwell. I contracted shingles, which was a sign of my weakened immune system and was the start of the collapse of my health. I had no choice but to take another week off as sick.

14. Shortly after the shingles outbreak, I had a massive arthritic attack and was hospitalised for three months, after which I was discharged for home care. Unfortunately, the Head Teacher and Admin Officer were unable to wait and see if I made a recovery, so the school governors took the decision to medically retire me from work. I believe there was an option to appeal this decision and put forward a representation, but I was too ill to pursue anything and the slim prospect of recovery meant there was little point in making a petition. In my mind I was still clinging onto the hope that there could be some improvement, but I was not sure whether this was the beginning of the end. Up until this point I had immersed myself in my career, but once that was taken away, I was at a complete loss.

Section 2. Impact on relationship

15. In May 1987, having become more obviously ill and constant fatigue, forgetfulness and night sweats, as Coventry City lifted the FA Cup, I felt a little more optimistic and met someone that it seemed I may have a future with, however limited that may be.

16. We purchased our first home together in August 1988, but HIV infection meant that obtaining a mortgage was not as simple as it should have been. Banks and building societies appeared intent on recommending endowment mortgages linked to life insurance policies. This attracted a lot of awkward questions about health, so contrary to the perplexed Building Society Manager's recommendation, I insisted on a simple repayment mortgage. As a result, the house purchase went through without any difficulty.

17. As described in part one of my statement, I was surprised when I met a girl who was interested in getting to know me romantically, even after I disclosed my infection. The pressures of living with HIV were profound, but we embarked on setting up a home together. However, as so often occurred, my fear of infecting someone else and all of the effects of living with the infection, would ultimately undermine the relationship. In the years that we were together, my health concerns became the biggest burden to the relationship. I often worried about her contracting the infection and potentially not being around for very long as a partner and in the brief moments when I found a stable ground, it would be her turn to worry. She was desperate to have children and start a family, but this was not possible (it was before sperm washing and safe IVF was introduced). We did discuss the possibility of adopting or fostering, but was told there was no point in attempting this because of how we would have been assessed by the social workers – I had an extremely life limiting condition and she would have been viewed as a potential single parent. The concerns about my health, my ability to take on a child and the prospect of my partner being a single mother were big enough reasons to dispel any hopes we had of being parents this way. We determined the likely outcome through informal conversations with

the relevant organisations and I saw no point in making an application as the writing was on the wall.

18. By 1989 and the beginning of 1990, we were going around in circles of what our future together might look like and it became too much pressure for two very young individuals to overcome. I felt as though I was wasting her time and became defeated by the condition. I could not see the point of being involved with someone that wanted all of the 'normal' life goals into old age, as I only faced constant disappointment. I therefore reached the stage where for her benefit and in order for me to tackle the illness, we had to go our separate ways. We were faced with barriers that were out of our control and we were not equipped to cope with it, we had no offer of support. I certainly wish things could have turned out differently, but in reality, the growth of the relationship was not possible. My final responsibility was to arrange a HIV test for her so that she could live a life free from all that I was burdened with. I would have been around 24/25 years old at the time our relationship ended and I chose not to pursue any further romantic relationships.

19. It was difficult to find purpose anywhere else. All the normal objectives in life; pursuing a career, setting up a home, starting a family and travelling the world simply evaporated.

Section 3. Impact on Health from 1990

20. The end of our relationship coincided with a major bleed and I was admitted to hospital. During the hospitalisation, a tray of medication was thrust upon me, which the nurse instructed me to take. I asked what they were for, but she was unable to provide an explanation and just remarked 'the doctor wants you to take them'. I was under the care of Professor Shinton at the time, who was very old school and his bedside manner was not the best. The nurse then asked if I was refusing to take the medication, which placed the onus on me – I was made to feel as though I was breaking the rules. A simple explanation was never provided. Fortunately, I was able to ask

another nurse for the British National Formulary (BNF) which provided key information on the selection, prescribing, dispensing and administration of the medicine, from which I discovered that it was AZT and Septrin.

21. Your world comes crashing down so many times with this infection, but on that day, it crashed around my ears – I heard about AZT so much in the news and what that meant in terms of my prognosis. This happened six years after I was first diagnosed with HIV and I had been told by my mother that something miraculous may happen, but I was now on the verge of having AIDS and from what I understand, my CD4 count had fallen below 200. I became extremely stressed and depressed following this discovery.

22. I knew the sister on the ward very well and she passed the information on to the haemophilia sister, Chris Titley, who came to see me as soon as she was able to. She explained what the purpose of the medication was and what it was needed for and apologised for how the doctor had thrust it upon me. Once I had been fully informed and got my head around the importance of the medication, I started to take it and was reviewed by Professor Shinton in his clinic a month or so later.

23. I was not told what to expect from the medication in terms of side effects, but shortly after being discharged from the hospital once my bleeding resolved I became very unwell. I suffered with an upset stomach, nausea, insomnia and had a constant feeling that life was not worth living. I explained the side effects to Professor Shinton. I was prescribed a high dose of AZT that was taken twice daily. I found that I was able to deal with the side effects better at night and would try to sleep through them. Professor Shinton concluded that the worst of the side effects were attributable to the Septrin, but wanted me to continue with the course of treatment. Despite this, I decided to stop with the Septrin completely and made him aware of this. I explained that I would cope better with just taking the AZT at night, to which he flippantly remarked ‘take it when you want, it probably will not work anyway.’ His comment reinforced the notion that I was fighting a losing battle.

24. The irony is that whilst AZT was a potential life saver, it was also a potential killer at the same time. It was a chemotherapy treatment so vicious that many individuals could not cope with such high doses of the medication. I opted to take the entire daily dose of AZT at night so that I could sleep through the side effects, in order to function during the day and hold down a job. I managed to do this for seven years and astonishingly it was possible to see that my CD4 count was gradually decreasing and I could detect that in time it could drop through the bottom of the graph.

25. I remained in the house that we had bought, but was living on my own in a depressed state and was terribly unwell. I was struggling with getting up and down the stairs, and started to look at more appropriate accommodation. Bungalows were invariably more expensive and without substantial compensation and relying on income from my work, which had been curtailed, I had to look for something affordable. I eventually found a bungalow that required a full renovation. My father had some time on his hands after taking early retirement, so we took on the project together. I was not in the physical position to do all of the work myself, so my father became a mainstay of support. My father carried out all of the manual labour and we tried to make the house as future proof for me as possible – we spent some time extending and modifying the property so that it met my needs and we finished the renovation a year or so before I started to become very unwell.

26. The year that I purchased the bungalow, I had an insight that my health was deteriorating and I came down with chicken pox in June 1992. Ironically, my mother sent me to chicken pox parties as a child, but I never seemed to contract it. It was not a good sign that I was getting childhood illnesses and becoming susceptible to everyday colds. My immunity was deteriorating and I was hospitalised with various drug resistant infections that indicated my health was not progressing in the right way.

27. In 1994, I started to experience a stuffy nose, which appeared to get worse over the summer. I initially put this down to a hay fever type condition, but I ended up losing my sense of smell and later struggled to breathe through

my nostrils. My hearing was also affected. An ENT doctor carried out investigations and it looked as though I had Lymphoma, which those infected with HIV are at increased risk to. Due to the haemophilia and the location of the Lymphoma (which was at the back of the nasal pharynx cavity), they were unable to carry out a biopsy as there was too much of a risk – there are many blood vessels at the back of the nose and a biopsy could trigger life threatening bleeding. It was, however, explained that because of the nature of Lymphoma in that area, it often was aggressive with a usual prognosis of 12 to 18 months.

28. I was referred to a cancer specialist, who discussed localised radiotherapy, but that was considered too dangerous because of the risk of bleeding in that area. It was decided that nothing could be done aside from regular scans, as any form of treatment would be just as devastating as the tumour itself. Yet again, I was dealt with another blow, but I was resigned to my fate because I had a death sentence from AIDS anyway. I felt very down and unable to do anything, but the fact that the mass was in such an awkward place to get to, in order for the diagnosis to be confirmed, I had a glimmer of hope to hold on to.

29. The Lymphoma diagnosis was devastating for my parents, who could see that I was trying to function and hold a life together, but I now had a condition which could potentially run its course in 12 to 18 months.

30. For a period of 12 to 18 months, I underwent regular MRI scans, watching the tumour gradually increase in mass – which explained why my hearing was becoming worse and I was having difficulty breathing.

31. After 18 months and totally unexpectedly, one of the scans showed that the mass had changed size and had shrunk without treatment. By this point, I was on a lot of medication, but was also using a visualisation technique to get the inflammation to go. I still experience stuffiness and a sense of congestion to this day, but when I recently saw an ENT specialist, they implied that it could have potentially been a case of lymphadenopathy –

where the tissue in the lymph nodes becomes enlarged because of an ongoing fight. This has become another stepping stone in my progression.

32. After my partial recovery from the potential Lymphoma, I took a holiday to the New Forest and came home feeling refreshed. However, a couple of days later, I became unwell and was diagnosed with shingles. I went back to work briefly after my annual leave, but my body was aching from head to toe and within a couple of days it completely stiffened up. The inflammation was so aggressive that my joints were seizing up. Painkillers failed to relieve the excruciating pain. I went to see the haemophilia consultant to understand what was happening and because I was unable to manage at home, I was admitted to hospital where I deteriorated further. My left elbow had completely fused, my wrists were partially fused and even my toes and feet were painful and could not be moved properly. After three months, I could not walk and required help with personal care.

33. When in hospital, the doctors were treating me with numerous anti-inflammatories to calm the infection. I was referred to a rheumatologist, who started to discuss the point at which AIDS began. This was when I truly understood that my situation was helpless.

34. I have a vivid memory of the consultant being outside of my room one day talking with his students and remarked that it is very difficult to determine when AIDS begins. I was so weak and unwell at the time that I did not have the energy to respond, but his comment was not particularly discrete. Hearing those words was very impactful and acted as another nail in the coffin, which struck at the heart of everything and confirmed why I was in hospital. I would have been considered an AIDS patient when my CD4 count fell below 200, so it was not a surprise that he was discussing this with his students, but it was very hard to hear those words aloud.

35. Before the hospitalisation I was around nine and a half stone, but my weight fell by approximately 50 per cent. There are pictures of me when I was discharged and I look like a skeleton, I was gaunt and had no flesh on me

at all. It was the same look as Freddie Mercury when he had AIDS. I was discharged home towards the end of GRO-C and in time for my 30th birthday. Home care was put in place for me at the bungalow, which had not long been finished, but I looked as though I was about to check out.

36. Carers would arrive in the morning to wash me and would manhandle me from my bed to the wheelchair, then to the sofa where I would be propped up with cushions. I was unable to sit up by myself or even feed myself and no medication intervention appeared to make any positive difference. I became entirely helpless, fully reliant on the carer and hit the realisation that my life was starting to become out of my control. I even had carers sleep overnight at the bungalow, which was an odd experience and a complete intrusion on my privacy and dignity. I was promised by the social services that the carers would be kept to a small team and eventually it was made more compact. It was hard shifting my mindset from being as independent as possible, to becoming fully reliant on strangers. I no longer had the strength to administer myself with my haemophilia treatment, so again had to rely on a nurse visit for this.

37. Mum would visit every day between the carers to keep me company. I suffered from headaches, so watching the television was not always an option. Mum would bring audiobooks for me to pass the time, because I was unable to hold a book. I was going mad, stuck in the four walls, hardly seeing anyone. Dad saw me when he could, but Mum was my main support. I do not think that my sister could handle the situation.

38. The social services became more involved as I required further care. A financial assessment was conducted by Coventry City Council, who proposed that I should sell my property and use the equity to pay for a residential home. There was no way that I was going to accept that. At the time, I had been medically retired, so my income was evaporating and the trust made it clear that it did not exist to replace my income. I had no choice, but to get my head around the benefits systems at a time when I was completely housebound. I also had to give up my mobility car, which had

been an integral part of my independent life. The only transportation support offered was Ring and Ride – a local authority mini bus service. This was open to the elderly as well as those who were unwell and disabled, so I never found that the service was accessible. I became reliant on ambulances to ferry me to and from hospital appointments.

39. I was really unwell and restricted, and so I started to instruct Mum (who was not best suited to technology and medical jargon) to seek advice on research related to HIV treatment and I began to receive the National AIDS Manual, produced by a charity to document developments with AIDS. I had been brought up with religious and spiritual beliefs but found myself struggling with them. I found myself thinking, if there is a God, 'you need to improve the situation to give me some sort of life or call it a day'. The research came as an answer and the manual was a gold mine to me. Miraculously, it was as if that prayer was answered and a couple of days later, I found that I was able to sit up. Further improvement came from the developments in medication.

40. At this point I had been given no specialist referral, and once I realised that combination therapies were coming through, I was advised to go back to my haemophilia doctor and ask for a referral to a specialist HIV doctor. This would have been at the end of 1996. I was told that another patient had been asking the same questions and was informed of a specialist unit at Heartlands Hospital, Birmingham.

41. In January/February 1997 a referral was made to the Department for Infection and Tropical Diseases at Heartlands. I arrived by ambulance in a wheelchair, with a blanket over me. I was six stone in weight and had mouth ulcers running all the way down my throat. I was keeping my fluid and food intake up, but my weight was still falling away. I explained that the HIV was taking its toll and blurted everything out from my research, even commenting on the medication I ought to be taking. The specialist listened to everything I had to say, which considering how I felt about medical professionals and what I had experienced before, this came as a total breath of fresh air. The

doctors at Heartlands became allies – they were relatively young and opted a modern practice of including the patient in the decision making. I found them to be very open and transparent and would listen, attributes which increased my faith in them.

42. My CD4 count was below 50 and it was an absolute miracle that I did not have PCP pneumonia as my viral load was rather high.

43. The new treatment marked a whole new chapter on survival as the medication regimes were so demanding. Some tablets had to be taken on a full stomach, some on an empty stomach and all had to be taken at specific times. My mother was the one who had to manage my medication and come up to me when the carers were not present and on the rare occasions that she could not be there, I felt so alone and vulnerable. It is incredibly difficult to articulate how distressing it was. I was prescribed a number of supplements to stabilise my weight and in May 1997, Dr White at Heartlands persuaded me to go back onto Septrin. From 1991, I had only been taking Fansidar, an anti-malarial drug that had some mild prophylactic effect against PCP with no obvious, intrusive side-effects. I carried on taking this until 1997 and I did not experience the same side effects as before.

44. There was nothing I could do to ease the side effects of the medication. My rapidly deteriorating condition meant that I required a personal assistant 24 hours a day, but the system did not allow for this unless I sold my house. No support was offered by the government and I felt that I was left on my own – I did not always have someone there when I needed them. I was mortified and felt awful for the carers, but they would just come in and do their job – my dignity was completely gone.

45. The medication managed to reduce my viral load and increased my CD4 count, but it lowered the effectiveness of my haemophilia treatment. For most haemophiliacs, the Factor dose would have been increased to relieve some of the symptoms, but because I had an inhibitor, this was not possible. I was on very specific medication that worked in the presence of an inhibitor

but it was not as effective in doing that. I consequently suffered with excruciating bleeds that were untreatable as the medication completely undermined the haemophilia treatment. It ultimately took around 12 months of altering the types of HIV medication, which in itself was a tricky thing to do as there was a risk of developing a drug resistance. When I went onto Saquinavir, my haemophilia improved, but I had a viral rebound and the medication had to be changed again. It was incredibly problematic. I found myself being a guinea pig, but on this occasion willingly because I was fighting for my life. Everything I did was motivated by the attitude of preserving my life until a cure or something revolutionary came along.

46. There were very limited options to treat my haemophilia; they could not keep upping the dosage of the medication because of the thrombotic effects. After a year of playing with medication, they eventually found a stable combination that reduced my viral load to undetectable and there was a correlation with my CD4 count improving. Two years after maintaining that progress, I was able to stop the Septrin. I recovered from AIDS and reverted back to a more stable condition. Effectively you can reverse the viral impact of HIV but usually you cannot reverse the other impacts it can lead to. Ironically, I then started to suffer with hay fever, asthma and eczema, but it was explained that the immune system can be overactive before it settles down again. The asthma was bad for a few years before it eased off and although I occasionally feel I need one, I now manage without inhalers.

47. In February 1998, the Department of Health approved recombinant Factor 8 for under 18s. I had been asking for access to recombinant products for some time because of the fear around vCJD and I was concerned that the Department had not approved it for my age category (to confirm I would have been 32 years old at the time).

48. In August 1998, I suffered a severe bleed in my left knee and the doctor on call was unable to find any of the factor replacement product that they were using on me at the time. It was of his view that I could have recombinant Factor 8 if it was my choice and consequently a couple of doses were

administered over the weekend. When Dr Strevens returned on the Monday, he was angry that I had received recombinant product and the doctor who administered it was reprimanded. From what I noted, this use of recombinant factor was not recorded in the UKHCDO database and I question whether it was intentionally omitted. To confirm, it was not until 2003 that the Department of Health approved the use of recombinant factor products for all haemophiliac patients.

HCV Treatment and Impact

49. By 2001, my HIV consultant established a joint hepatology clinic with Professor Mutimer. Up until this point, my haemophilia centre had not made any referral to a liver specialist in regard to my hepatitis. The HCV infection had been dealt with in house, which basically meant monitoring blood tests.

50. My HIV consultant was concerned that my HCV infection had been unaddressed and so Professor Mutimer started to see me at his liver unit. After a number of tests, I was told that I was genotype three and that my viral load was particularly high. It was of Professor Mutimer's view that I was incurring damage to my liver because of the active infection and that I needed treatment to address that.

51. The treatment for HCV at that time had been alpha Interferon and Ribavirin, but Professor Mutimer advocated Pegylated Interferon and Ribavirin and a 12-month course of treatment (as opposed to six months) to increase the possibility of eradication. I was unaware that Pegylated Interferon was still on trial at the time (it was described as the gold standard medication) and so Dr Mutimer required approval to finance the treatment. This was approved and I began the course of treatment.

52. Undergoing the treatment was comparable to being on a rollercoaster. As soon as the medication was administered, I found myself completely wiped out with the worst flu like symptoms. I could not function at all and would be bed bound for a couple of days. Once the symptoms started to ease, I

regained some functionality, but not long before the next injection of Pegylated Interferon and so the cycle would repeat again.

53. Along with the flu like symptoms, my skin became red and itchy. My mental state was severely impacted and I became short tempered, irritable and depressive. Having heard the horrific side effects experienced by other patients, I ruled out the whole year in order to undergo the treatment.

54. I attended regular clinic visits during the 12 months, in order for my viral load to be monitored. Each appointment confirmed that the viral load was decreasing dramatically, but I was told that they would discontinue the treatment if it increased at three and six months. Fortunately, I remained virally suppressed and completed the full 12-month course in 2002.

55. I achieved a full virological response to the treatment, which the doctors described as eradication of the virus. Despite being told this, I had reservations over whether the virus could lie dormant and repeatedly questioned medical professionals. This was something that I became aware of through my own independent research. Those who were deemed to be 'cured' from the virus, still died from the long-term exposure to HCV and this remained a contentious issue in my campaigning and discussions with the medical profession. Eventually, as part of my negotiations with the Department of Health, we reviewed the extra hepatic effects of an infection with HCV and considered Occult Hepatitis C Virus (HCV) Infection (OCI) – defined as the presence of HCV RNA in hepatocytes or peripheral blood mononuclear cells without detectable HCV RNA in the serum.

56. In my opinion, I felt that the virus was suppressed beyond detection following the 12-month course of treatment, but I was never reassured that it was completely eradicated from my body and that it could not cause any further damage. As far as the doctors were concerned, the liver was capable of regeneration over time and there were no further concerns, but I was not comfortable with this hypothesis and continued to challenge medical

professionals. Fuelling my fears was the fact that I still did not feel well enough to consider it a cure.

57. Following the HCV treatment, I had a discussion with the consultant about the ongoing risk of developing liver cancer and so, six-monthly scans were arranged. He could not argue with the evidence presented – that other haemophiliacs were still dying as a result of the long-term exposure to HCV. Before the conversation, he was prepared to discharge me from the clinic based on the fact that I had 'eradicated' the virus. Had I not challenged the lack of follow up care, it would not have been implemented.

58. Interestingly, despite being told that the liver is capable of regeneration, my Fibroscan results did not dramatically improve following treatment and I continued to have a fatty liver. This was a direct consequence of the HCV infection and posed a future risk to my health. No medical professional ever explained that once the liver disease is detected, the possibility of regeneration is questionable.

59. I did have the opportunity to challenge the notion that a patient was fine post treatment as a result of my campaigning and negotiations with the Department of Health. This helped to argue for a review by the Medical Expert Panel who advised the Department of Health in regard to scheme reform.

60. I found that the psychological impact was profound long after the HCV treatment had finished. My resilience was undermined and I felt depressed, compounding how I had felt with the HIV treatment.

61. I felt significantly more fatigued than I was prior to starting the HCV treatment. The doctor dismissed this assertion and commented that he had not recognised this with other patients, unbeknown to the fact that I knew other patients in the clinic who were making similar health complaints. He was also rather dismissive about a pain in the right upper quadrant of my

liver post treatment. He could not comprehend how I was not ecstatic following a successful course of treatment.

Trial of Interleukin-2

62. In the middle of my HCV treatment, I was in contact with a friend who lived and worked in America. It was through this association that I came to hear about some promising results relating to Interleukin-2 as an antiretroviral therapy for HIV. I shared the subject at my next review with the HIV consultant, who appeared interested in what I knew about the medication, but informed me that there were no trials at present in the UK. Miraculously, I received a phone call shortly after the consultation to say that a trial had been set up in the UK to assess Interleukin-2 and whether I was interested in becoming an applicant.

63. There was no guarantee on whether I would be on the placebo or Interleukin-2, but I jumped at the opportunity and was chosen as a participant. It later transpired that I had been allocated Interleukin-2, which threw up at bit of an anomaly because participants were not supposed to be on certain other medications and I was still being treated for HCV at the time. Nevertheless, the medical professionals involved approved the co-administration and I was approved access to the trial in 2002.

64. I was still recovering from the profound damage caused by the HIV infection between 1997-8 and was of the mind that I needed to tackle the infection aggressively in case I experienced a viral rebound. I constantly lived in the fear that the virus had not gone away and it was a case of 'when' rather than 'if' it would come back with a vengeance. I therefore felt compelled to give the trial a go in my attempt to have some normality in life.

65. The trial involved a subcutaneous injection, much like the pegylated Interferon and because it stimulated the immune system, it produced similar side effects to the HCV treatment.

66. It felt like it went on forever with the amount of severe side effects it had that many patients could not tolerate and so they discontinued their treatment as a result. Each dosing cycle lasted five days, and injections were administered every six weeks, whereby the five-day cycle would restart again.

67. Treatment began in May 2002 and ended in November 2003. I then had one booster cycle in October 2008. The study finished in November 2008.

68. Because of the severe nature of the side effects we were required to keep a diary. I can remember the treatment vividly. Incredibly high temperature – it was the worst fever that you can imagine. I was shaking to the point of almost convulsing, and burning despite the medication – with my mother wiping my brow. It was horrific for my mum to witness. While I was on the five-day cycle, my mother would stay with me as I was so ill.

69. Vigorous medical checks were carried out to monitor both my temperature and any side effects. I ended up constantly taking antipyretics – both paracetamol and ibuprofen to lower my temperature, which peaked at 44 degrees.

70. The side effects of the medication were rather intrusive, very challenging and went on whilst I was actively receiving the treatment. My skin, as if it was not inflamed enough from the Pegylated Interferon, became bright red and shed, and I tried every cream in an attempt to ease the inflammation.

71. I think most people could not understand the extent of pain, fatigue and the psychological impact of the trial, but I was in desperation to start winning my battle with HIV.

72. My mother was stoic throughout the trial. I often shook as a result of my high temperature and at times she had to call for medical intervention because I was on the border of having convulsions. The doctors were prepared to

lower the dose of treatment, but I wanted it to have the best opportunity and declined the offer.

73. I carried on for as long as I was allowed. The purpose of the medication was to increase the CD4 count of a patient to within the normal range. A drop in CD4 count is indicative of a compromised immune system and although mine had improved with combination therapy, this was to give it a boost.

74. The trial of Interleukin-2 improved my CD4 count dramatically, although this did not necessarily translate into a lower mortality. Whilst it seemed to have a lasting effect on my CD4 count (which although dropping from the original higher level, still remains around 700-800), this was not the case for everyone. Accordingly, the medication did not become a mainstay in HIV treatment as it did not translate into better outcomes and the side effects were horrendous for patients to endure.

75. When I had finished the first six cycles, I was informed of further side effects to treatment that I was unaware of.

76. My HIV consultant since explained that whilst my CD4 count may recover, it is missing a lot of information that it previously contained. Metaphorically, he used the analogy that HIV knocks out the keys on a keyboard, which can return with effective medication, but they are not labelled and you do not recover the useful information.

Change in HIV Treatment

77. In 2009, the doctors thought they could swap one HIV medication to another without any issues, but I ended up experiencing a severe drug reaction, similar to a withdrawal from a Class A drug. Initially, there was a huge improvement, I experienced no brain fog, my energy levels increased and I found that I had a good night's sleep even on a couple of hours. Unfortunately, it lasted no longer than a week and I soon deteriorated rapidly – I was taking longer to fall asleep and waking up earlier and earlier until I

could not sleep at all. My memory was atrocious and I started to struggle with severe depression and fatigue. The medication I had been taking before could only be taken in the evening as it had tripping effects and patients often had vivid dreams. Doctors originally inferred this as a sign that the medication was working well in the brain, but soon acknowledged the negative psychoactive effects.

78. The medical professionals did express a concern that the neurological deterioration could be due to vCJD rather than the HIV medication, so I was sent for an MRI. The scan did not show the typical holes in the brain that were associated with vCJD, but it did indicate premature ageing of the brain. It was a possibility that this could be due to the HIV infection or inflammation caused by HCV, but the doctors were unsure. As there was no confirmatory test for vCJD, they were left in limbo over the diagnosis and had no way of differentiation.

79. After a change in the HIV medication, the psychological effects significantly calmed down, but I had already suffered three months of insomnia, depression and suicidal thoughts which coincided with a family holiday in the New Forest. I thought that a break away would be good for my mental health and that the fresh air would help me relax and sleep better, but it turned out to be horrendous. The caravan was not fully accessible for my wheelchair, so I slept out under the awning, but the rain was so heavy at night that it pounded through me. At this point, I was unaware that my insomnia was due to the medication.

80. I soon reached a point where I became so low and I no longer wanted to be here. I was very suicidal and in complete despair. I went out in the forest on my own and phoned the clinic. Usually there is no signal but astonishingly the reception was clear and I was able to speak with Dr Taylor at Heartlands. Once I explained how I was feeling and what I had been experiencing, he made arrangements for me to go to the clinic and receive psychological support.

81. The medication was reviewed and gradually changed until I felt better. I had to fill out a form to confirm that I had experienced a severe adverse reaction to the medication. Another stable medication was found shortly after and my mental state improved, but this does not negate the long-term damage caused by the experience. I felt that my resilience had been undermined and I could no longer cope with pressure or stress. The lasting impact from the HCV medication was profound enough and this experience further exacerbated my fragility.

vCJD

82. In February 2001, I received a letter asking whether I would like to be informed if I had received batches of Factor 8 implicated by potential infection with vCJD. I asked to be notified, and on the 27 February, I was told that I had received implicated batches of Factor 8. Once again, this information was incorrect on the UKHCDO database.

83. I cannot describe the anger I felt during and after the consultation, considering I had persistently asked for years to come off plasma product. It proved to be another cost exercise and once again people's lives had been put at risk because the Department of Health were not prepared to take action quickly enough. I was incredibly saddened to recognise that the government would put haemophiliacs in this position.

84. No psychological support was offered alongside the information. I did ask for a face-to-face meeting, but this was to confirm the news, rather than provide any counselling.

85. In 2004, I received further communication to state that I was 'at risk' for public health purposes – a status I later discovered was assigned to all haemophiliacs who had received blood products.

86. In March 2008, I made contact once again with the Haematology Department at Coventry for clarification about my at-risk status, but I never received a response to my email.

87. After I had transferred to Birmingham, I was contacted by Dr Oliver Chapman who had taken over from Dr Strevens as Head of Haematology at Coventry. He first communicated in February 2009 to clarify what had happened to a patient that had died while infected with the prion. As the prion had no cause in the death, there was evidence that it could lie in a dormant state.

88. I revisited this again in 2017 and heard back from Dr Oliver Chapman. He communicated that there had been a lookback in 2004 and it was discovered that I had not received implicated batches of Factor 8. Shockingly, this reinterpretation was never made clear to me and I did not find out until I made a second attempt at contact, some 13 years after they first became aware.

89. During this time, I required an endoscopy in relation to my HCV infection but the procedure was delayed a number of times. I had suspicions that the vCJD notification may have influenced this delay, but practice eventually changed and the Department of Health allowed the reuse of surgical instruments. The endoscopy was performed soon after the regulations were amended and whilst I was told the delay was not because of the vCJD, the timing supported my suspicions.

90. To this day, we are still unaware whether vCJD has effects other than the rapid deterioration of the brain and there remains a lot of uncertainty about the disease.

Impact on Health Since 2017

91. Since 2017, my life turned into a complete rollercoaster and not long after the Panorama documentary and Preliminary Hearings of the Infected Blood

Inquiry, everything has snowballed in terms of my mental and physical health. Had this not been the case, I would have provided much more information to the Inquiry over the past five years, particularly in relation to the independent research I have conducted and material from my intense campaign period. The timing of everything has been unfortunate although I am confident that the Inquiry has captured this evidence.

92. Mentally, I became very depressed, which did not fit with the general mood at the campaign given the progress achieved and considering the Public Inquiry had been announced. Tainted Blood chose to move on without my involvement, and I started to suffer with a number of health issues, GRO-D

GRO-D

93. Within weeks of the Panorama documentary being aired, I had trouble with urine retention and was admitted to Accident and Emergency because I was unable to pass water. I was also starting to experience random spasms that were completely unexplained, my fatigue was off the scale and I reached new levels in terms of 'brain fog'. Following many investigations, a number of crystals and stones were detected in the urine, as well as bladder cancer cells.

94. The bladder cancer diagnosis came as a huge blow, and whilst no medical professional will ever commit themselves to the cause of the disease, I was aware that the HCV treatment had a negative impact on the kidneys and I certainly had suspicions that my co-infection of HIV and HCV was attributable.

95. Shortly after the cancer diagnosis, I underwent a transurethral resection through the urethra. The surgeon then scraped away the surface lining of the bladder to remove the cancerous cells. The procedure was followed by a course of localised chemotherapy, which was successful.

96. Within a short period of time, I once again had problems with urine retention and further investigations revealed that my bladder had refilled with crystals.

Once again, I was suffering with persistent urine infections and spasms, which were put down to kidney stones, and so my bladder was flushed with a sterile liquid. This was followed by a course of strong antibiotics, but these kept failing and the infection would return.

97. When researching commonalities between spasms, fatigue and kidney stones, I found a condition called Hypercalcemia – a condition in which the calcium level in the blood is above normal. At my next review in the HIV clinic, I asked the consultant whether my calcium level was out of kilter. He went through my recent blood samples and commented that whilst the calcium was mildly outside the normal range, it was not alarming. Despite his assurances, when I researched this further, I found that a slight abnormality could still be an issue.

98. I urged for this to be investigated and was referred to an Endocrinologist at the Queen Elizabeth Hospital, Birmingham. I was diagnosed with hyperparathyroidism, where an enlargement of one of the parathyroid glands causes overproduction of the parathyroid hormone and causes high calcium levels in the blood. The diagnosis was confirmed by a scan and I was informed that I potentially required surgery on my throat. The prospect of surgery was rather daunting considering the concern over whether FEIBA would control my bleeding.

99. Over Christmas 2017, one of my wisdom teeth cracked beneath the gum and my dentist could not do anything to save it. Interestingly, one of the issues heard by the Inquiry is that haemophiliacs are at an increased risk of dental decay and their teeth tend to be more fragile. The last time that I had a tooth extracted, I nearly bled to death and so the thought of undergoing the procedure again induced much trauma. My tooth was extracted in January 2018 and I was instructed to continue with FEIBA to control the bleeding,

100. Unfortunately my gum was still bleeding two weeks after the dental procedure, despite FEIBA providing several clotting factors in an attempt to

stop this. As luck would have it, I had been in contact with a research nurse about early access to HEMLIBRA, however patients are supposed to have any coagulant therapies completely out of their system before starting treatment. It was decided that because I was continuously bleeding anyway, I could stop taking FEIBA and within a couple of days I could safely start HEMLIBRA. Once I did, the bleeding completely stopped. I have always been a guinea pig, but this time it was through my own choosing and I found the treatment life changing. HEMLIBRA had been in the pipeline as a prescription medicine for those with haemophilia A, with or without inhibitors, but I had been recommended for.

101. Consequently, when I required parathyroidectomy to remove a tumour affecting the parathyroid gland, I spoke to the consultant about how the bleeding would be controlled. During our discussions, I was told that whilst HEMLIBRA caused clotting so effectively, there was a risk of going too far the other way and causing thrombosis if other clotting agents were added, which was equally dangerous. It was agreed that NovoSeven would therefore have to be administered at the point of surgery. But we would have to monitor and adjust dosing depending on the effect observed.

102. The parathyroidectomy went ahead on 26 March 2019 and I was administered NovoSeven, as well as HEMLIBRA beforehand. The surgeon reported that there was no bleeding whatsoever and whilst this was good news, there was still a concern of why there was none at all. The NovoSeven dosage was reduced in response and they decided to shorten the length of time that I received it in addition to the HEMLIBRA.

103. I recovered well from the surgery, but ended up with a tingling sensation down my neck. The consultant was concerned that this may be caused by thrombosis and so a full body scan was taken, which detected that I had thrombosis in the superior mesenteric artery. It can cause abrupt cessation in the primary blood flow to the majority of the small bowel as well as the ascending colon and can also cause neurological effects.

104. There was a debate over whether the new treatment caused the thrombosis or if it was due to a previous treatment. Unfortunately there were no previous scans to compare. I was prescribed aspirin to thin my blood, but this counteracted the HEMLIBRA and did not deal with the thrombosis. It was agreed that taking aspirin was not the best idea in terms of quality of life and so I am just living with the thrombosis in the superior mesenteric artery. Other blood vessels around it have expanded because of the pressure.

105. After removal of the diseased parathyroid gland and a further bladder wash out and course of antibiotics, my bladder problems resolved.

106. Marcus Green, Consultant Orthopaedic and Arthroscopy Surgeon at the Royal Orthopaedic Hospital, Birmingham, agreed to take me on as a patient despite being a very complex case. I have a lot of pain in both knees and my left hip as a result of bleeds into my joints and the viral arthropathy, and so he came up with a treatment plan to tackle my damaged joints with surgery and physiotherapy. It was proposed that my right knee would be replaced initially and they would continue with the left knee once I had built up the strength on my right.

107. Everything was put into place and I had a pre-operation assessment on 25 February 2020. Unfortunately, I came down with an infection on 29 February and so the surgery was postponed until 16 March. The surgery was cancelled once again as a result of COVID 19 and during this time all face-to-face appointments (including my physiotherapy) stopped. I felt that I was moving backwards in terms of pain, especially in my left hip.

108. Due to interruptions caused by COVID-19, a follow up examination took place in 2022 and confirmed that no cancerous cells had returned in the bladder. Accordingly, I was discharged as a patient from that clinic.

109. Post COVID-19, I was reviewed once again by Marcus Green. My left hip took priority going forward because of the pain and so the initial plan

was scrapped. My left hip was replaced in January 2022 by hip surgeon David Dunlop and whilst I was able to handle the large operation, little was offered in terms of post operative physiotherapy. I had noticed how physiotherapy for haemophiliacs was being cut prior to the pandemic, but it became a complete struggle to obtain anything afterwards.

110. I wrote a formal complaint to the medical CEO of the Queen Elizabeth Hospital, Birmingham explaining how I had been neglected as a patient post-surgery and how there had been no offer of physiotherapy or psychological support. To their credit, my criticism was taken seriously and they acknowledged how changes to their service developments were essential. My complaint is still very much live, so I will have to wait and see if the CEO is true to their word. Whilst physiotherapy hours have been increased, there is still much more to be done.

111. As a result of the backlog caused by the pandemic, I have only just been scheduled for a left knee replacement, but at least following my letter of complaint, I am receiving some regular physiotherapy to maintain, if not improve, its condition before the operation.

112. My left knee is a very complex case and because it was injured whilst I was still at school, it stunted the development of the bone. The bone is very thin and as it has been left so long without physiotherapy, the tendons and muscles that surround it are shorter. The surgeon will have to remove a sizeable amount of bone and shorten the leg so that it is nearly straight. I have been told that the worst outcome of the surgery is that the leg will still not be straight enough to stand on, but that I should be pain free. The best result is that I will have a leg straight enough to put weight on and raise enough to use a walking frame.

113. Even with surgery, I do not think the prospect of being able to fully walk again is on the cards.

114. I also have damage to my elbows and wrists, but surgeons are very limited with what they can do on smaller joints. The arthritic episode in 1996/97 caused so much fusing of the joints and whilst the inflammation has gone down, the damage has been done. Technology is not quite there to help with the range of movement in these joints by surgery.

115. My physical challenges are a result of the haemophilia, combined with the irreversible damage caused by HIV and HCV. Virologically, my HIV is stable but I am not cured, and I will have to continue lifelong medication and I hope it remains effective.

116. I now struggle orthopedically and it is a challenge for me to write or use a keyboard as I experience elbow and wrist pain from lack of normal joint function.

Impact on private and social life

117. I used to love reading but this hobby has fallen by the wayside as a result of my ill health over the years. I am no longer able to retain information that I read and the intense concentration required to read has an anaesthetic effect, which is attributable to the brain fog that I suffer with. It can even be challenging to do things in bitesize pieces because you break the train of thought and the fatigue and tiredness also takes its toll.

118. I used to love caravanning and campervanning with my family, but it has now been years since I last went on holiday. As I started to become less mobile, it was not possible for me to get in and out of a caravan. There are accessible campervans, but they cost in excess of £85,000 to purchase – the cost of everything disabled-access based is phenomenal because it is not in high demand and consequently the manufacturer has a monopoly.

119. It was often the case that you had to declare a HIV test to your employer and insurance companies, regardless of the result. As a result many

haemophiliacs had to pay higher premiums or were denied insurance policies altogether.

120. In 1985, I travelled to America with a group from Trelors and because of my haemophilia, I had to apply for a VISA waiver. A special piece of paper was placed in my passport and so I was marked as 'different' to immigration. On the plane, they introduced a new form where you had to declare if you had AIDS or whether it was suspected. From what I remember, I think I relied on a technicality as my infection with HIV had not progressed to AIDS. Nevertheless, I was waiting for the tap on the shoulder once we landed and I fully expected to be escorted back to the UK.

121. My HIV positive status also caused administration problems on a family holiday to Canada and I had to make contact with the Canadian Authority. I would have to go through the same process if I was to return, but it singles you out from other travellers, which deters you from visiting.

Section 4. Campaigning and Other Initiatives

122. The illness inflicted on me coupled with the burdensome legal system preventing justice ultimately motivated me to become a campaigner. My experiences of seeking recompense through the legal system, first with my injuries that occurred at Sherbourne Fields School when I was under their care, and secondly in relation to HIV and Hepatitis infections from my NHS treatment, demonstrated the legal barriers to obtaining any form of justice were formidable. Besides having to battle a system that was financially stacked in favour of powerful organisations like government I had the resultant ill health and personal financial risk with which to contend. While supporting a bereaved family affected by the contaminated blood scandal, I later learned that obtaining justice via an inquest was similarly fraught with legal, financial, personal and health challenges that were simply not a consideration, let alone a barrier, to organisations like government.

123. I formed the view an Inquiry was the only fair way to provide an opportunity for all sides to be heard, for appropriate legal support to be provided, evidence scrutinised, and an unbiased view established that could generate more appropriate recompense and lessons for the future. The added scandal in the infected blood saga is that it took nearly 40 years to obtain such a suitable Public Inquiry.

124. In the mid-80's my attempts to obtain compensation and an inquiry were largely limited to writing to my MP, Geoffrey Robinson seeking his support. My mother for her part had written a letter appealing to Margaret Thatcher directly, not just as Prime Minister but as a mother who had experienced the worry of potentially losing her son when he was lost for a time in the Dakar rally in 1982.

125. In 1988/89 this changed when I was approached by David Watters of the Haemophilia Society to see if I would be willing to do a TV interview for Central TV news. I was at work when I received the call but managed to get the afternoon off. I was particularly nervous about revealing my identity as stigma at that time was rife. Former college friends had their homes attacked and others I knew had lost jobs just from their HIV status becoming known. My mother had even witnessed the worrying attitudes of colleagues and neighbours within her work place. Doing this was a massive thing for me. Taking account of my concerns, the interview took place, filmed with me in silhouette, and discussed the potential for ex-gratia settlement by government and my feelings about the amount suggested. I was later invited to take part in a Central Weekend Live programme in November 1990 but my health prevented me from doing so.

126. The Macfarlane Trust was established and ex-gratia payments eventually received, but it took a while to become clear that the level of ongoing support was not the generous package promised by government. However, by that time, I was battling with ill health and fighting to survive the effects of HIV.

127. As a result of new HIV combination therapy eventually stabilising my health, in 2001, I felt I had the strength to renew, through Geoffrey Robinson MP and Lord Philip Hunt, my call for comprehensive compensation to be paid for each infection sustained and for a Public Inquiry to be established. By this time Hepatitis C was also a significant concern and had become a focus for the Haemophilia Society campaign too. My requests for compensation and an inquiry were denied with the government feeling HIV and HCV were "not comparable" and that although it was known that heat treatment could inactivate viruses in blood, regrettably the technology did not exist until the mid-1980's to do so. On my call for a Public Inquiry, the government response was "we do not think it is the way to go forward".

128. My health took another blow during treatment for HCV in 2001/2 but afterwards I renewed my efforts to help others and progress the campaign for justice.

129. I heard about the Haemophilia and Life History Project ran by Sian Edwards through my involvement with the Haemophilia Society. Sian was based at the University of Brighton and conducted the project between 2003 and 2007. I was notified by the Haemophilia Society and agreed to take part and meet with Sian. During our recorded conversation, I spoke about the impact HIV had on my life and my disappointment over government payments. My story was online for people to listen and it was another experience which prompted me to become involved with campaigning. The timing was fortunate considering I had just recovered from my experience with Interleukin 2 and HCV treatment, and the fact that I was able to put my face and story into the public domain just prior to the Archer Inquiry. Please refer to http://www.livingstories.org.uk/categoryaudio_id_10.html for the full interview.

130. I assisted the Haemophilia Society in establishing its first Inhibitor Support Group for people and families living with Haemophilia, and an antibody therapy, it soon became obvious that it was urgently needed.

Considering as many as 15 per cent of patients will develop an inhibitor in their lifetime, I found rather surprising that it had not been addressed before.

131. At the time I was using a product for those with inhibitors called FEIBA. Whilst it was effective at treating bleeds, the main drawback was that it was plasma based and not recombinant.

132. Through the work of the Inhibitor Support Group, we soon discovered that people from smaller centres had never heard of FEIBA – further highlighting the need for the group, to share information and developments amongst its members. It was likely smaller haemophilia centres were withholding products that could be beneficial to their patients because of the lack of funding and the cost implications. This practice urgently needed challenging and thus I continued with my involvement in the group.

133. In 2009 I supported the Saving Lives charity by sharing my story and advocating for early HIV testing and treatment. My doctor at Heartlands, Stephen Taylor was a founder of Saving Lives. A charity existing to combat the stigma and promote testing for HIV. He asked whether I would provide my story in an attempt to encourage others to come forward and undergo testing. My interview was filmed in 2009, which provided a face and background story to the early campaign.

Please refer to https://www.savinglivesuk.com/positive-people/positive-ambassadors/joe/ for my full interview.

134. Having recovered from my immune collapse that almost took my life 10 years previously, I now felt stronger and optimistic about the Archer Inquiry. I felt that too many people infected as a result of the contaminated blood scandal still lived in fear of speaking out and that was a key reason why the government felt able to avoid addressing the issue comprehensively. Therefore, I started to participate in radio and television interviews about my personal experience and also expressed concerns about vCJD.

135. I had suffered from the stigma associated with HIV and HCV, which was the primary reason preventing individuals from speaking publicly and joining campaigning efforts. I had already lost friends and my job, which were two common fears preventing people from campaigning. I discussed everything with my family, who would be stigmatised by way of association if I spoke publicly about my infections, but they were happy for me to disclose everything in the public domain to raise awareness in regards to the contaminated blood scandal.

136. When the Archer Inquiry commenced, I attended the hearings with my mother. The building was not wheelchair accessible, which was completely illogical considering a large number of the haemophiliac population had mobility issues and were wheelchair users. Surprisingly, it was not the first time that I had experienced this, even at the Haemophilia Society events.

137. I was contacted by V J Meehan, the Solicitor at the Inquiry and I was invited to provide a written statement. I was still poorly at the time and computer technology was rather limited. Writing has increasingly become a real issue for me because of the damage to my joints, but I had a small early PC and I managed to put together a statement.

138. The Archer Inquiry did not have a legal team akin to the Infected Blood Inquiry, who are able to meet with witnesses and conduct statement interviews, so it was left to the individual to put together a statement independently. At the time, I did not have access to the Internet, had little mobility to get to the library and did not have any subscriptions to any medical journals, so I was unable to reference information in the way that I would have liked. Nevertheless, I spoke about my personal experience in great depth and included some of the evidence I had gathered.

139. I did not provide oral evidence at the Archer Inquiry, but I attended most of the hearings and spoke with a number of journalists, including one from the Telegraph and some from the local Coventry press where substantial articles with photographs appeared.

140. My attendance at the Inquiry proved to be useful – I gained a wider understanding of the efforts made on the campaign front and I was noticed by Gareth Lewis of Tainted Blood.

141. In 2010, I had been campaigning alongside the Haemophilia Society and I was invited to speak in front of the Haemophilia Alliance on 13 April 2010. I initially presumed that it would be a small meeting with a few attendees, but my presentation, along with expert presentations, were also attended by the full Alliance membership including the Department of Health, UKHCDO (Professor Frank Hill) and the UK Haemophilia Societies plus guests Dr. Pat Hewitt of National Blood and Transplant, Professor Bob Wills of National CJD Surveillance Unit and Mr. David Prior, chair of the CJD Incidents Panel. The presentations were also filmed.

142. I spoke about the need for a reliable diagnostic test for vCJD, highlighting the uncertainties I suffered. The absence of a test during a serious 3-month long medical emergency made it unclear if the neurological symptoms I had were related to my HIV medication or vCJD infection. During the meeting, the Surveillance Unit were very optimistic that with the correct funding from the Department of Health, they would have a diagnostic test within a year. In their presentation that followed, the Department of Health confirmed that the necessary financing would be made available and there would be no obstacles to prevent the diagnostic test.

143. The main message I took away from the conference was that anyone receiving blood products was at a cumulative risk of vCJD (regardless of whether it was an implicated batch or not). If a donor was infected with the prion, because they remained undiagnosed, they would have carried on donating blood unknowingly and therefore those receiving blood products were potentially exposed to abnormal prions. The medical professionals confirmed that the more blood products received, the higher the risk of being exposed to the abnormal prion.

144. It later transpired that there was internal resistance to the diagnostic test and the Department of Health were not prepared to tackle other knock-on implications. Cleansing wash solutions were devised to prevent the transmission of prions from patient to patient via surgical instruments, but they never came to pass and the Department of Health instead opted to wait and see the extent of the problem. Unsurprisingly, the funding never materialised for the prion diagnostic test and 12 years on from the meeting, we still do not have a test available. As is often the case, the reassurances evaporated and turned out to be meaningless.

145. Around this time, I also received a phone call from the CEO of the Haemophilia Society, Chris James, to say that for the campaign to make progress, he had been informed there needed to be a debate in the House of Commons. I mentioned that I had a good relationship with my local MP, Geoffrey Robinson, who was in a good position because he was part of the Labour party and was well acquainted with members of the Backbench Business Committee.

146. Simultaneously, Natasha Engle, a member of the Backbench Business Committee was also looking for relevant issues that would not normally make it into the main chamber, so I mentioned to Geoffrey that Natasha may be sympathetic to the matter. He went away and shortly after he came back to say that the contaminated blood scandal had been approved for debate on 14 October 2010. I notified Chris James of the rapid development and felt that my involvement had contributed to the positive outcome. I now had the confidence to campaign beyond media interviews.

147. Just after obtaining the House of Commons debate, I agreed to be part of Tainted Blood. There was discussion with Gareth Lewis, one of the founders of Tainted Blood, who asked if I would be willing to join the Tainted Blood campaign.

148. Gareth Lewis and Andy Evans as founders of Tainted Blood brought those affected by the contaminated blood scandal together and encouraged them as a mass voice to pressurise the government.

149. Shortly after I joined Tainted Blood in 2010, Gareth Lewis passed away whilst on holiday in Spain. He had seen the House of Commons Debate on 14 October and the Westminster Hall Debate in the November of that year, so he witnessed how the ball had started rolling again. Nevertheless, his death was a significant blow to the group and we were left in limbo on how to progress with campaigning.

150. Besides pursuing publicity on the issues, I ended up conducting research into the medical aspect and found ways to access medical publications.

151. I was of the opinion that we needed more affected faces in the media and that we should base our arguments on the facts rather than generalities. A lot of people spoke angrily towards the government, with a great depth of emotion, but they needed to include statistics and science-based evidence for the government to respond.

152. As part of discussions with Bernard Manson at the Haemophilia Society, I started to work on figures that may be appropriate to move the scheme forward in terms of being able to live and not merely exist. I discovered that the Haemophilia Society were essentially rethinking the levels to which they could support the campaign as the Archer Inquiry had taken its toll.

153. There did not appear to be the appetite to continue campaigning and I noticed that even the word itself had been dropped from their literature. I did challenge Bernard about this during the Haemophilia Society's AGM and the it appeared the movement of Tainted Blood's campaigning persuaded them to become more engaged again. The society renewed their efforts for more communication with the government and we did eventually make progress. The Haemophilia Society was always viewed as the 'mainstay' by

the government, but the noise made by Tainted Blood, and other voices, received attention and moved the campaign forward.

154. The House of Commons and subsequent Westminster Hall debate led to a number of openings and opportunities to meet with the Secretary of State for Health and other department officials. I, along with other senior Tainted Blood members, spoke to Jason McCartney, MP in 2011 to explain about Tainted Blood and its campaign, and he came on board with great effect. I tried to build a successful dialogue with the Department of Health and wanted Tainted Blood to be taken seriously as an organisation.

155. Once the Penrose Inquiry was called, we were not invited to take part in the same way that we had with Archer because it concerned Scotland only. Nevertheless, we as a group attended landmark hearings. The doctors took centre stage at the Inquiry and it was described as a 'whitewash' by the campaigners. The Inquiry was very dismissive of our criticisms of the Department of Health, although they did lack the statutory power to compel them to provide evidence and attendance of relevant witnesses to address this.

156. There had been a great expectation for the Scottish Inquiry to act in interest of the 'victims' but it was another missed opportunity. Once again, the outcome played into the government's hands and brushed off our genuine concerns. It was a very frustrating and disappointing conclusion for those affected by the contaminated blood scandal. I am aware that Lord Penrose had personal issues during the Inquiry, but the fact he was not present for the publication of the final report was a sad indictment.

157. What became clear quite early on after joining Tainted Blood, was that a number of campaigners had different views on what should be the campaign focus. Accordingly, I often attempted to act as a peacemaker.

158. Some campaigners left Tainted Blood to pursue a campaign that pushed aspects related to the HCV support structure and not restricted to

haemophiliacs. I had sympathy for their position, but the rest of the Tainted Blood committee did not want to align with that thinking and when the opportunity for a meeting with the health minister arose, I felt it would be a missed opportunity not to be involved. I had the perspective that everyone affected by the contaminated blood scandal needed to have a voice and so I negotiated to attend the breakaway meeting, which constructively helped obtain a systematic review on extra hepatic effects of HCV.

159. I took up co-chairmanship of Tainted Blood alongside Sue Threakall in 2013. I noted in her statement to the Infected Blood Inquiry that I joined Tainted Blood in 2013, but this does not accord with my timeline and I presume she is referring to when I took up co-chairmanship.

160. At this point, I represented Tainted Blood at numerous meetings of beneficial groups (the Macfarlane Trust, the Skipton Fund, the Caxton Foundation), which often occurred in London. Considering the state of my health, it was surprising what I was able to do. I was in need of a double knee and left hip replacement and the fatigue and brain fog made everything challenging.

161. Again, through my involvement with the Haemophilia Society, I participated in a 'buddy' project for Novo Nordisk in 2013. A 'Buddies Book' of personal stories and photographs was produced and is another example of how we shared information about haemophilia and raised awareness.

162. 2014 proved to be a productive year and there were a number of progressions in the campaign.

163. The Haemophilia Society informed me of an Inquiry by the Science and Technology Select Committee and after registering an interest Tainted Blood were subsequently invited to provide evidence on 5 February 2014. They made a number of recommendations, yet I am not sure whether they were enacted. Their report named 'After the storm? UK blood safety and the risk of vCJD' can be found here:

https://publications.parliament.uk/pa/cm201415/cmselect/cmsctech/327/32702.htm

164. Following campaign and legal pressure, the government established a systemic review of evidence. An EPPI Centre review took place in February 2014 and Tainted Blood provided evidence to explain the physical effects of HCV beyond the liver. An EPPI Centre report was published named 'Depression, anxiety, pain and quality of life in people living with chronic Hepatis C'. I have a copy of this report in my possession, shall it be required by the Inquiry. It can also be found here: https://discovery.ucl.ac.uk/id/eprint/1473446/1/Brunton_%282015%29.pdf

165. Following the EPPI Centre review, in 2015 I was invited to take part in a workshop by Ginny Brunton at University College London. I received an invitation to attend and whilst it was something I pursued on behalf of Tainted Blood; the offer was made as a result of my own initiatives. The workshop was made up of UCL academics, influencers and policy advisors looking at the issue of public engagement such as the contaminated blood issue. It was a difficult matter, in need of resolution and they were conducting research on how such matters should be addressed.

166. I made a joint presentation with Ginny Brunton entitled "A case study of advocacy group engagement". I talked about my efforts as a Tainted Blood campaigner, our engagement during a systematic review and how we attempted to push for an Inquiry via an Inquest, along with the problems with access to legal aid and funding. I raised the question on how anyone was supposed to legitimately challenge the government when they were potentially the source of the problem all while they were controlling access to legal aid and denial of an inquiry. I advocated that the only way to bring about any form of resolution and closure was a Public Inquiry and to engage with those affected, with their often-differing opinions, as to what would bring about closure.

167. As part of our campaigning efforts a group of Tainted Blood and Manor House Group campaigners met with Karen Ashton of Public Law Solicitors previously used by Andrew March (a prominent member of Tainted Blood). One of the aspects of interest to us was the European Convention on Human Rights Act Article 2 – the right to life and in particular the requirement for prompt, adequate depth of investigation. We felt that we could explore this and drive an Inquiry through a review of previous inadequate inquests or by applying it to a current Inquest, similar to how they did in Scotland with the Penrose Inquiry.

168. Stuart Fuller, a friend from college and prominent campaigner sadly passed away in May 2012 and the official concerned with signing his death certificate felt his particularly traumatic death, which he felt was as a result of his infection through contaminated blood products, should be referred to the coroner. In talks with his family, I found that they were interested in pushing for the best Inquest possible to record why he died. I explained our thinking regarding Article 2 and they were agreeable to the objective of using it to push for a Public Inquiry. This was pursued with the legal support of Karen Ashton and the matter was then referred up to HM Senior Coroner for Milton Keynes, Thomas R Osborne.

169. The process was a battle from the start for Stuart's family and as the main support between them and Tainted Blood, incredibly frustrating for me to witness.

170. Funding legal support was a major challenge. Legal Aid reform by government had made support harder to attain and one of the significant issues for denial of support by the Legal Aid Authority was that they did not accept that 'there is any wider public interest in the client being represented at the inquest to determine what, if any, historic systemic failures may have occurred in the 1970s and 1980s'.

171. The government are able to control how legal aid works and who has access to it and so they leave those who are vulnerable the choice of expensive legal action or to push for a Public Inquiry, which they often resist.

The funding responsibility therefore falls entirely on the injured party, a concern the government does not have.

172. The process was extremely protracted with the Senior coroner initially appearing uncertain and failing to understand the issue. He seemed resistant to the idea of a Public Inquiry. Once the Department of Health were invited to become party to the inquest it was noticeable that the long-held government line of “the risks were not known and benefits of treatment far outweighed any risk” became the prominent view. It felt like David vs Goliath, the battle was with the entire system and the family were not being listened to.

173. Eventually the Senior Coroner accepted that Article 2 was engaged but also accepted the Department of Health representations and findings of the Penrose Inquiry to the extent he felt capable of conducting the Inquest.

174. After many inexplicable delays, almost five years after Stuart’s death, the Inquest produced a narrative conclusion on 24 February 2017 that read: "He was diagnosed with haemophilia as a child that contributed to his death. He also died as a result of HIV and hepatitis C infection that he contracted after receiving contaminated blood products given for the treatment of his haemophilia. In particular the HIV infection resulted from the administration of imported blood products from the United States of America administered between June 1981 and April 1982. At the time that the blood products were given to him the risks of infection were not known and the benefit of such products far outweighed the risks of infection. The circumstances of the use and contamination of the blood products were dealt with fully in the Penrose Report following a public inquiry under the Inquiries Act 2005 published in March 2015."

175. We were all disappointed with the outcome of the inquest which we felt had failed to identify the reasons behind why Stuart had received infected blood products. Stuarts family had been through a gruelling, emotionally distressing time because of the delays and lack of urgency shown by the

coroner, and having been alongside them the entire journey I felt emotionally drained and very disillusioned with the system.

176. The battle proved to be with the whole system, not just making a case to the coroner for a suitable inquiry. It was also an uneven battle with the Department of Health having comprehensive legal representation throughout and able to defend their view that the issues were not systemic. Despite substantial pro bono legal support and minimised costs, none the less the financial challenges were substantial and the entire personal financial risk lay with the family. This barrier and the emotional distress caused were primary reasons why the coroners ruling was not taken to Judicial Review despite the strength of feeling held.

177. Having proven that Article 2 was engaged, apart from the significant emotional burden, we realised that with substantial fundraising in support of such an inquest that it may be possible to argue for a full public inquiry in the future. I spoke with other bereaved families who had a similar interest and so as a campaign group, Tainted Blood offered our assistance in guiding them through the process. However, it was not necessary as the Infected Blood Inquiry was announced that same year. Further details about the impact of the Inquest are contained in the witness statement of GRO-B GRO-B. Permission was granted by Stuart's family for me to share this account.

178. The experience drove me to think that Tainted Blood as an organisation needed to move to a more professional stance and conduct formal fundraising activities that did not curtail our ability to campaign. We could not obtain charity status because of issues surrounding campaigning and we were not willing to be restricted in the same way as the Haemophilia Society.

179. In reality, I was asking committee members to implement evidence driven responses going forward. There was a difference in opinion and others did not want to operate at such a diligent level – they wanted Tainted

Blood to remain as a social voice calling for change, but not arguing over the specifics with scientific evidence.

180. Other initiatives not greeted well by other senior members of Tainted Blood included the push for a Hillsborough style Inquiry. I pushed for this when I met with Alistair Burt and eventually when I met with Andy Burnham. I was communicating with Fred and Eleanor Bates as Andy was their local MP and they had a constructive relationship with him. The proposition of a Hillsborough style Inquiry started to take hold and was another pressure present when Panorama went out in 2017.

181. At the time, a number of media opportunities were arising and Adrian Goodyear, a fellow campaigner, had contacts to Panorama. I had also been speaking to Jason Evans, who was communicating with Panorama as well. Amongst others, I was able to bring the Trelors story to the fore and it was broadcasted on 10 May 2017.

182. The various angles of campaigning came together around the time that Panorama aired and it was only a matter of weeks before Prime Minister, Theresa May announced on 11 July 2017 that there would be a public inquiry. I felt that the efforts of all campaigners contributed to this by imposing so much pressure that the government could no longer resist the call for an inquiry.

183. The differences in Tainted Blood once again came to the fore and a number of members (including the founder) formed an action to oust me as co-chairman and restructure the group, with Andy Evans at the head. I GRO-D and severed ties with Tainted Blood as my position became untenable. Ultimately, we were of a difference of opinion, and a number of those within the group did not agree with the approach that I was trying to pursue.

184. Since stepping away from Tainted Blood, Jason Evans has applied my favoured approach effectively and with a huge impact. My hat goes off to

him because he is doing an incredible job – particularly with tackling the waivers imposed on financial assistance from 1991 and presenting the evidence found in The National Archives.

185. Prior to COVID 19, I was involved with the establishment and development of the Haemophilia and Bleeding Disorder Counselling Association (even though I have not received any form of psychological support myself.) Christina Burgess has taken this forward and I am proud to have been part of the effort. HBDCA now collaborates with a number of haemophilia centres across the UK to provide free psychological support.

Section 5. Treatment, Care and Support

186. I have not received or been offered any psychological support or counselling in relation to my infections. The only assistance I have ever received came from my HIV unit.

187. No counselling or psychological support was offered alongside the HCV treatment in 2001/02. I was only offered support from Heartlands during my acute phase and there has been nothing from the Haemophilia Centre.

188. The most beneficial psychological support I have received occurred as a result of a physiotherapy appointment. One of the therapists also ran a group session that focused on a patient's lifestyle, which encompassed their sleeping and eating patterns. I came away from the group therapy feeling as though I had some tools in my armoury that I could apply to other circumstances.

189. I have tried to deal with my psychological challenges as best as I can and I am making progress to tackle the remnants of the damage which has left me fragile and far less resilient.

190. I am caught in a quandary with the counselling offered by the England Infected Blood Support Scheme as I do not know what approach is best for

me personally. I do suffer with post-traumatic stress disorder and this will have to be addressed in any support that I receive.

191. I was never referred to any virologist, as the haemophilia doctors tried to manage my care in house. Initially, I received no specialist input beyond the haemophilia unit, which was a huge failing and meant that I missed out on early trials of medication. Between 1996-97, a lot of experimental treatment was starting to come through, so the potential was certainly there.

Section 6. Financial Assistance

192. When the Macfarlane Trust was established in 1988, I was still coming to terms with my positive HIV status and so on. My initial thought was that I needed help and I spoke to the chairman of the Haemophilia Society Alan Tanner who was initially responsible for the MFT. The process in obtaining help was straightforward at that point and I received support in moving house, such as for a washing machine to help cope with the extreme night sweats associated with HIV infection. At the time, I thought it was not a bad start and whilst it was not labelled as 'compensation', it had the potential to be a formidable support structure.

193. What came afterwards let the entire haemophilia community down. In their very first newsletter, published in 1988, the Macfarlane Trust said they had been tasked by the government to deal with issues, such as life insurance. I still have the original factsheet, and the assurances have still not been addressed.

194. I found the later process of applying for grants somewhat like going cap in hand for help and so avoided applying, even though the initial regular pay established at £20 a week in November 1988 (and backdated to November 1987) was entirely inadequate.

195. By 1995, my house had become inappropriate for my health needs. I could not afford a well-maintained suitable bungalow so I purchased a

bungalow in need of substantial refurbishment and with my parents' assistance set about modifying/repairing it. I approached the MFT for help and was required to have an Occupational Therapist assessment before a grant could be offered, even though the help sought/provided was a small proportion of the cost involved.

196. By December 1996, I was seriously ill and in desperate need of support. The MacFarlane Trust helped towards care provision for around six months, but wanted alternative sources of funding to be explored.

197. In around May 1997, an electric wheelchair assessment was carried out by Coventry Wheelchair Services. I did obtain an indoor electric chair and later an indoor/outdoor chair, which provided me with more flexibility. It was not until the MacFarlane Trust was eventually wound up though that I was given a one-off grant as a special payment toward a hybrid manual/powered wheelchair.

198. Around 1997/8, after being medically retired and losing a substantial part of my income, Tudor Williams from the MacFarlane Trust again visited me at home to say they could only offer assistance by way of a loan for a stake in my home. I refused this, but now understand that those who took this offer later had the charge on their home removed by the Terrance Higgins Trust. At Tudor's visit, I felt as though I was being interrogated as he started to look around my renovated bungalow and wrongly assumed that I could afford everything myself. I felt like my living standard was being judged more than noting the damage that had been done to me.

199. Because my health had deteriorated so much, I then needed a heavily adapted vehicle with a wheelchair lift. The Macfarlane Trust first required me to exhaust other sources of assistance before asking them. I approached Motability but due to funding constraints they could not help at that time.

200. I purchased my first adapted van privately. It had a petrol engine and I bought it from a Scottish gentleman who had it serviced every month. It was

well looked after, had a side lift for access and pilot seats, so as my health improved, I was able to drive again. It helped restore a more positive outlook.

201. The MacFarlane Trust would only grant £6,000 assistance, around 50% of the purchase price, with £4,000 on loan. I had to make the repayments out of my monthly financial support payments.

202. Twelve years later I did apply successfully to Motability for help but now, very expensive adapted vehicles needing a financial grant from Motability have strict qualifying criteria and I no longer meet those criteria because of the effect of my infections. Specifically, I am not in full-time employment, or full-time further education, not a parent or carer, and it is unlikely that my exceptional number of hospital visits would be reason enough to continue accessing the scheme. Personal and social reasons are not enough to qualify. Funding such a vehicle in the future is now a massive worry as without it I am essentially housebound. This is a massively important financial issue for me that remains to be resolved even with the new EIBSS scheme.

203. There were other times I sought help with care support that was not covered within my basic Social Care package (e.g. for a social or holiday event) but I was told the Macfarlane Trust were not there to compensate for the inadequacies of the care or benefit system, so my needs went unmet.

204. When my health stabilised, I successfully sought grants towards essential equipment, repairs to my adapted van and a manual wheelchair, for which I had to have another Occupational Therapist assessment. Far from the grants process developing and improving I found the scrutiny and need to justify my need for a grant had become even more burdensome and off-putting.

205. Later, with Mark Simmonds support I attempted to address my needs by making a case with the MacFarlane reserves during the Trusts 2012 “=mc” exercise. My identified needs and proposed request amounted to about

£60,000. At that time, I became ill and was hospitalised. This meant that I was unable to complete the paperwork and I did not receive anything from the reserves at all. After discharge from hospital, I spoke with the Trust, I was told the CEO, Jan Barlow, did not consider being in hospital as an exceptional enough reason not to have returned the necessary paperwork in the allotted time. The matter was closed, I missed out and never made another grant application until the trust was wound up.

206. Even when I was stuck in hospital unable to re-establish care support for discharge, I was told that the MacFarlane Trust did not exist to resolve the inadequacies in the social care system, which ultimately discouraged me from making a request for support. This came at a time when the trust was under much criticism.

207. Because of the strength of criticism, a meeting was held by Martin Harvey for registrants of the MacFarlane Trust. This was held at a premises without disabled access and so I was denied the opportunity to attend because of my mobility issues. There was a complete lack of regard towards the community they were supposed to be helping.

208. I did attend some of the beneficiary partnership hearings, but everything seemed to fall on deaf ears and made little difference. I could not understand why they did not utilise all of their budget to support beneficiaries and how they failed to address beneficiary needs.

209. When I was first introduced to Professor Mutimer in 2001, he acknowledged that it was terrible for haemophiliacs to have been infected as a result of the contaminated blood scandal and he felt that we were due compensation for what had happened.

210. Despite disclosing his views on compensation, I was never directed to the Skipton Fund by Professor Mutimer, albeit he sounded rather supportive when I informed him about my subsequent application.

211. Considering our conversations in regard to financial support, and the damage HCV was likely to have inflicted on me over 20+ years, I was utterly shocked to read his contribution to my application – particularly where he detailed there was no obvious damage to my liver. Consequently, my application for a Stage Two payment was refused as I did not meet the necessary criteria. However, the Stage One payment I received was later enhanced after scheme changes were introduced and the psychological impact of my infections was acknowledged.

212. Unbeknown to me, Professor Mutimer was on the panel assessing applications to the Skipton Fund. He never disclosed this to me at the time and I found out much later. I strongly believe there was a conflict of interest considering he was my consultant and also involved in considering my application for financial support.

213. Throughout the life of the Macfarlane Trust and Skipton Fund I found myself reliant on family and friends, which is not acceptable. There should have been a means of support provided to those infected as a result of the contaminated blood scandal to live and not just to exist and, to acknowledge the contribution/impact on parents.

214. Whilst the interim payments from the EIBSS are welcome, they are a mere drop in the ocean and are quickly spent on necessary equipment, transport, housing and care needs. I have received a letter notifying me about the £100,000 interim payment, but I will welcome the final report made by Sir Brian Langstaff in relation to financial support.

Section 7. Other Issues

215. There is no medical treatment to undo the damage caused by the viruses I contracted as a result of the contaminated blood scandal. Even though my HIV infection is under control, the arthritic damage is permanent for life and I am sure that the HCV has left a lasting legacy on my liver.

216. Even if there is a cure for everything I have been exposed to, hearing the evidence and forming a closure from the Inquiry is the best I will get. All compensation can ever bring is some comfort, as no amount will ever replace my longing for a family of my own, my career or the worldwide travel that I hoped to do. My motivation throughout campaigning was having a Public Inquiry to deal with everything fairly and listen to those infected and affected.

217. The government have battled to keep information about the contaminated blood scandal in the shadows and for those infected and affected not to have the truth. It is important that everything is exposed, but this should have happened years ago, so that we could have heard from government ministers, doctors and specialists who were involved in decision making.

218. From listening to Kenneth Clarke, it is ingrained in those left who were involved in the contaminated blood scandal, that they did everything they could to avoid the catastrophe that occurred. They have denied so many times that there were systemic problems. I find it frustrating that government officials will not change their stance, even after all of the evidence presented in front of them states otherwise.

219. I have been unable to retrieve copies of my medical records from certain hospitals and from Treloar's. GRO-D GRO-D GRO-D and whilst I knew the broad timings of events, it was important for me to be specific because of my struggling memory and brain fog. I did go to the GRO-D but my

health at the time meant that I could not progress the matter and I had to let it go.

220. I am in total admiration of Sir Brian and his team in their endeavour to uncover everything in relation to the contaminated blood scandal and I hope that the final report will bring closure. I have always wanted the voices of those infected by the scandal to be heard and for the evidence to be scrutinised fairly. From the Infected Blood Inquiry, we have heard an honest, transparent assessment of what happened and everything has been laid bare – whilst this has been painful to hear, we have a clearer picture of how the scandal transpired.

221. As the Inquiry draws to a close, it has become apparent that there is a need for the community support we have received to continue and I would like to see something implemented for those infected and affected besides any compensatory arrangements.

222. In providing a brief update to the Inquiry on the day of signing my written statement, I have now received my knee surgery and I am currently recovering. Although the surgery did not go as we had hoped and I will not be able to walk again due to the lasting effects caused by the viruses. The damage caused by the viruses are still causing me major health issues today. Science and technology will not reverse the lasting damage and the lasting effects that I am still living with today.

Statement of Truth

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

Signed GRO-C

Dated 13 April 2023