

Witness Name: GE Walker
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GWYNNETH ELAINE WALKER

I, Gwynneth Elaine Walker, will say as follows:-

Section 1. Introduction

1. My name is Gwynneth Elaine Walker of GRO-C Derbyshire, GRO-C My date of birth is GRO-C 1957. I am divorced with three sons. I work full time as a planning enforcement officer at Chesterfield Borough Council.
2. I prepare this statement as an affected mother of Steven David Walker (date of birth GRO-C 1980) who sadly passed away on 6th August 2017 aged only 37 as a result of receiving contaminated blood products.
3. **This statement has been prepared without the benefit of access to Steven's full medical records.**

Section 2. How Affected

4. Steven suffered with severe Haemophilia A with a clotting factor of less than 1%. This condition was identified by experts at Hull Royal Infirmary shortly before Steven was aged 2. The diagnosis came after several upsetting events in which Steven sustained unexplained injuries which led to a number of abuse allegations against Steven's father and me. There was no known history of Haemophilia in our family prior to his diagnosis.
5. Steven was infected with Hepatitis B, Hepatitis C and HIV as a result of receiving contaminated blood products and was at high risk of developing cvCJD.
6. Steven attended Hull Royal Infirmary and Bristol Children's Hospital in his early years, where he received cryoprecipitate for treatment of haemophilic bleeding. In December 1983 we moved to Norwich and Steven's care was transferred to the Norfolk and Norwich Hospital where his haematology consultants were Dr John Leslie and Dr Alec Black. I believe they will both have retired now. The sister who initially looked after Steven was Celia Shilling and she was later replaced by Gill Pout both of whom became my '*sort of friends*', through the regular contact that developed. It was at the Norfolk and Norwich Hospital that Steven was first given Factor VIII which was sometime during 1984.
7. During 1984, I was encouraged to learn how to mix the Factor VIII and taught by Celia Shillings to give this to my son by intra-venous injection, at home. I was apprehensive at first but the frequency of incidents requiring treatment coupled with the various experiences in Accident & Emergency convinced me it needed to be our new modus operandi. I was provided with a sharps disposal box and understood the need to ensure sharps were disposed of safely but I cannot recall any information being shared, explaining that the medication could contain infections that might harm my little boy or that from receiving treatment, he could infect me or my younger child. I remember being exasperated when I contracted hepatitis B, from Steven to learn far too

late that so much more care was needed. I can remember my feelings of horror that I needed to protect my two year old from my four year old.

8. In conversation with the hospital staff at the Norfolk and Norwich Hospital, I understood that they were aware of which batch had been infected with the HIV virus. They knew it to be a batch that they had supplied, for me to administer, at home. At the time, I was required to keep a record of the date, time, batch number and number or units of Factor VIII I had given, on every occasion. This information was submitted to the Haematology Unit periodically but I have not retained copies of this information as so many years have now passed.
9. At no point was I given any information or advice regarding the risks of infection from the use of Factor VIII to Steven or of the risk of infection from Steven to me or other members of the family.
10. Steven was infected with Hepatitis B and HIV sometime during 1984/1985 and I do not know when he was infected with Hepatitis C.

HIV

11. Celia Shilling made a chance remark to me in the corridor at the Norfolk and Norwich Hospital stating that they had previously been asked to screen all their patients (without informing me) and that she did not know what it meant but that my son had tested positive for HTLV III. She thought that it could be a good thing that he had developed antibodies as they knew he had been expose to 'something' and some other patients had not. This was interesting because she knew that my son had been infected and it was mistakenly revealed to me. This conversation was at a regular review appointment sometime during 1984/1985 but I cannot be certain of precisely when.
12. I was "*formally*" told by Dr A Ashman, my GP at Brundall Medical Practice, that Steven had been infected with HIV on 31.12.1985. He was not able to give me much information but he was sympathetic about the fact that my son had been infected with HIV.

13. I was offered an appointment with the infectious diseases specialist but told this could only be provided to me at the GUM clinic which was the sexual diseases clinic in order to discuss the fact that my 4 year old son had HIV. I was a respectable young woman in my twenties and was recently separated from my husband. It was terribly humiliating for me to attend this place and especially in these particular circumstances. I was given very little information to enable me to understand and deal with Steven's HIV infection and only attended twice as I found the experience intimidating.
14. I was provided with no further information at this time or any information or advice regarding the risks of transmission of HTLV III to Steven or the risk of infection from Steven to myself or his younger brother. At this time, Steven was a child who sometimes resisted being treated by me which necessitated the fact that I had to hold him down, which inevitably put me at more risk of infection, but all unbeknown to me at this time.

HEPATITIS B

15. In or around November 1985 I became seriously ill and my GP, Dr Ashman, through blood tests, confirmed I had developed Hepatitis 'B'. He immediately made the link that I was likely to have contracted this through cross infection from my haemophilic son. At a follow up appointment on 31st December 1985, Dr Ashman confirmed that Steven had tested positive of Hepatitis B and also for HIV. I was later told by a consultant at the Norfolk and Norwich Hospital that Steven's Liver Function Tests (LFTs) indicated that he had likely contracted Hepatitis B around February 1985. I remember Steven running his hand along a fence and getting a splinter and I sucked the splinter out and I believe that this could have been how I became infected. I was angry that the potential for infection and the potential for cross contamination have never been discussed. I had never heard of hepatitis.
16. I was given insufficient information to allow me to manage or deal with both of our infections with Hepatitis B.

17. Following on from my Hepatitis B infection, I was tested for HIV at six monthly intervals until the consultants must have decided that the level of risk to me was minimal due to my acquired knowledge of the risks and my diligence to be careful.

HEPATITIS C

18. As Steven became more grown up he wanted more responsibility. He took over his own treatment and moved out and became independent in or around May 2000. I do not recall being told that he was infected with Hepatitis C but have a discharge note from the RVI in Newcastle dated 20.09.1993 which states that Steven is HIV+, HBsAg+ and HCV+. These were abbreviations on a form rather than a diagnosis that had been explained to me. Hepatitis C used to be referred to as non-A, non-B and I have a vague recollection of this being mentioned in passing. The reason I knew that he was aware of his Hepatitis C infection was because he received financial support from the Skipton Fund.

Section 3. Other Infections

19. On 20th September 2004 Steven and I both received a letter to say that we had both been put at risk of vCJD. This was yet another thing we had to deal with and was another factor at the back of our minds. We could not really deal with what "*might be*" as we were already struggling, trying to deal with what was already and it was horrific.

Section 4. Consent

20. It is my belief that Steven was tested for Hepatitis C and HTLVIII without his or his parents knowledge or consent.

21. I believe Steven was tested for hepatitis B, following me becoming ill with the condition, in November 1985. It is likely that I consented to this at the time, although I cannot be certain.

Section 5. Impact

22. On 23rd October 1991 I received a letter from John Leslie, Consultant Haematologist at Norfolk and Norwich Hospital in which he writes:-

23. *"As you may have heard on the grapevine we are ceasing the issue of Monoclate P. Consensus of views at the UK Haemophilia Directors' meeting on 7th October was that the scientific evidence supporting the use of Monoclate P in HIV positive haemophiliacs is unconvincing and that fact, combined with the estimated cost per annum of well into six figures, has convinced me to take this action".*

24. He goes on to say they are transferring to BPL 8Y intermediate purity Factor VIII. It seems to me that the best care available, was too good for those who had already been handed a death sentence.

25. In December 1991 when Steven was aged eleven, we moved house to Middlesbrough. His father and I had actually separated before he was diagnosed with HIV infection and subsequently divorced but due to the pressures of looking after a very poorly child and younger sibling, we got back together and tried to make the relationship work.

26. From Middlesbrough, Steven's care was provided at the Royal Victoria Infirmary in Newcastle (RVI) which was some 56 miles north of our home and our choice of location was no accident. Steven was treated with Monoclate P Factor VIII at this time. A discharge note, following a period of admission, dated 20.09.1993 states that Steven's diagnosis was chest infection, suspected pneumocystis (CPC) and it noted his status as Haemophilia A (severe) HIV + / HBsAg + / HCV +.

27. Indicators such as viral load and CD4 counts were closely monitored and prophylactic treatments such as monthly intravenous plasmas to increase the white blood cells and a nebulised treatment to protect against the risk of a specific form of pneumonia called CPC were given. Steven began to object to the treatments and a referral to a child psychologist was made, who supported his father's and my opinion that Steven really did not want to be told or discuss details of his condition. He was a bright boy; I think he knew but didn't want to be confronted with it.

28. In 1993 when Steven was aged 13 he was told about his HIV status.

29. Steven had not managed in main stream secondary school at the local comprehensive, due to bullying, so his father and I took the decision to move him to a very small private school. Advice was taken from Public Health in London, in 1985 and it was agreed that Steven's school would be informed of his Hepatitis B status but not the HIV status, on the expectation that adequate precautions would be taken to cover the risk for one infection, along with the other.

30. In those days, even medics were in fear of this disease. In hospital he was barrier nursed, in isolation, with staff in masks and protective gear and his food was brought on disposable plates with disposable utensils. There was a stigma associated with people who were infected and we couldn't even confide in extended family members, for fear of the secret getting out.

31. In the summer of 1995 we moved to Aberdeenshire due to the Steven's father's employment. Steven's care was therefore transferred to Aberdeen Royal Infirmary, specifically to the Infectious Diseases Unit. Steven's health was poor during the 4 ½ years that we lived in Scotland. Steven didn't attend school but was tutored at home for an hour a day, often at his bedside.

32. We had a party for Steven's 18th birthday but it had to be at home because he was too ill to go out. His special invited guests were his nurse from hospital, his home tutor and his driving instructor who had agreed to give him

lessons consisting of only 30 minute durations because Steven was too tired to manage a whole hour.

33. In January 1999, we relocated to GRO-C Derbyshire, where we still reside. Steven's medical care was transferred to the Haemophilia Centre at Royal Hallamshire Teaching Hospitals NHS Trust.

34. Steven was 19 years old and at this time the triple therapy was improving the quality of life for people with compromised immune systems. However, this was only short lived for Steven.

35. Steven started to attend a further education college and tried to socialise with people of his own age group. However, neither venture reaped success.

36. Steven was totally exhausted for much of the time, following the simplest and mildest exertion. He wasn't able to attend college for a full day and struggled to keep up with the workload and other students. Steven had missed an important part of his development in terms of mixing and socialising with others of his own age group, only having adult company apart from his family.

37. Steven had a brief relationship with a girl and the difficulties of progressing this become acutely obvious to him and this distressed him greatly. He moved out of the family home and became fiercely independent but he fell short of living a fulfilled life. Depression set in and thoughts of suicide crossed his mind and he recorded this in a diary.

38. Feelings of despair and the hopelessness of his situation resulted in him choosing to stop taking his prescribed medication for the viruses. He had been taking a concoction of various drugs at various times of the day and night, some with food, some an hour before food, some three hourly, others four hourly. He had set his alarm on his watch to remind him when he needed to take medication and it seemed to Steven, to be pinging all day long. Every tablet reminded Steven that he was unwell and self-pity and despair were never far away.

39. Steven was physically frail, underweight and described as being medically anorexic. His whole persona oozed vulnerable and some people took advantage of him. On one such occasion, he was robbed of money by being taken to various cash machines to draw out all his money and anything of saleable value was taken from his house to include the television and play station. In fear and desperation, he had to give up his independence and move back to the family home.
40. Steven's triple therapy was altered from time to time and he had a handful of occasions when he suffered such severe side effects to the medication that he was hospitalised. More regularly, the side effects were less severe though difficult to manage on a daily basis, such as chronic diarrhoea. Steven began to fear being out in public as this happened several times and caused him great embarrassment.
41. Into his twenties, Steven ventured to live alone again and over the following ten to fifteen years, his living conditions and his general wellbeing gradually deteriorated.
42. Throughout Steven's life, his wellbeing has been a huge concern for the family. He didn't complain or grumble to us, he just struggled on quietly despising his life and his lot. He sometimes hid away at Christmas and other such family events, like weddings because he didn't want his own misery and hopelessness to sadden the rest of us and spoil the occasion.
43. Steven strived to learn new things. He signed up for and achieved excellent grades in various on-line courses that kept his brain active and passed the time. Always, Steven undertook these courses because he hoped one day to contribute positively to the community and society as a whole.
44. Steven longed to have an intimate relationship with a girl but he was open and honest about his condition, with people he became close to and no relationship progressed. He wanted to be a father and he once told me about

one of his recurring nightmares, where he dreams he is ecstatically happy and making breakfast for his daughters, only to wake to feel the emptiness and misery in the knowledge that this will never be.

45. Steven used to go to the local pub and often drank to excess. He suddenly stopped going out altogether and explained that people abused his generosity at the bar. He said that watching people having a good time, all around him, while he was alone in a crowd made him feel miserable and then having to go home and be alone, was too distressing. He continued to drink to excess each evening and into the night. He also turned to illegal drugs, including heroin, in a bid to escape his own horror. Steven went 'cold turkey' and came off the heroin after years of dependency. He remarked that the withdrawal effects were insignificant, in comparison to the side effects of some prescribed medications he has endured over the years.

46. Steven didn't go to bed. He spent most of the last six years, or so, of his life on his sofa. He suffered from constant pain and used alcohol to mask both physical and mental pain. He said, to move from the sofa to a bed would wake him from any possibility of sleep. In winter he would be housebound because the pain from the arthritis was so debilitating. On a good day the highlight of his existence was a trip to the supermarket. This impacted on his mental health but he would not consider taking anti-depressants because he said he was already taken enough medication.

47. Steven didn't really recognise himself as someone with a mental health issue. In truth he was suffering from severe depression and anxiety and often had suicidal thoughts. He was self-neglecting to a point where the medical team at Hallamshire set up a Safeguarding Procedure under the Care Act 2015.

48. Amongst Steven's papers, I found something he wrote:-

"I am the planet, I am dying.

Dying of a virus, an infection that consumes all and gives nothing.

I have intelligence but was deprived of education.

I cannot have a job, I cannot give back.

I am the virus!

I must die”.

49. Steven liked to cook but often didn't have the energy or appetite to eat what he had made. His strength rarely stretched to cleaning up and his living conditions became quite squalid. He would not allow me to tidy up or even put rubbish out in the refuse bin for him because he saw my intervention as interference. He once explained that to accept help was to admit failure. There is no doubt that Steven was angry and the only people he saw to verbalise and express his anger to, were the people closest to him, who were feebly trying to help.

50. He has no friends and no social network. His younger brother, Chris, and I were his only visitors and most other contact with people was at the Hospital. He was often angry and rude to the consultants, who dealt with him very humanely.

51. In the last 4 or so years of his life, he did allow his younger brother to go around and clean up for him. Chris visited, socialised with Steven, shared jokes and played computer games and also cleaned the house as best he could in the time he could spare.

52. However, I was furious about the way the DWP conducted itself. They would carry out a review of his eligibility for benefits and this was always an excruciatingly painful process for Steven. I would do my best to take the stress of this away by completing the forms and just getting him to sign them. However, I always had to read to him what I had written because he was an intelligent man with rights and this was about him and an occasion could present, when he may need to answer for himself and without me being around to help. I worried a great deal about how he would manage if I died before he did.

53. Steven's existence was a daily struggle. Words can't describe how hard and how sad every single day was for Steven. Of course he could not block out the details of his misfortune but relaying this time and time again, to complete strangers, in a system where the assumption is that you are embellishing and exaggerating your ailments and are really a lazy scrounger who is trying to obtain benefits the government doesn't want you to have and regularly threatens to take away certainly destroys any self-worth you might have clung on to. Each time these review occurred, Steven's self-worth would decline further and it would take months for him to get over the effects of the process.

54. Aside from Steven's blood disorder and his subsequent infections, Steven also suffered from acute eczema which was present all over his body and distressingly uncomfortable. The presence of open wounds which would weep and bleed, added to the risk of infection both to Steven and from Steven to others around him. Steven suffered from the herpes virus and often developed cold sores that would appear in clusters on any part of his body. Strict hygiene measures were implemented, within the family which included a ban from others sharing cups, cutlery or a can of drink with Steven and never sharing food or toothbrushes.

55. I hadn't appreciated just how much pain Steven was in because he didn't tell me or complain. I hadn't realised that he was unable to manage the stairs where he lived until I found empty milk bottles, filled with urine, in the kitchen because he couldn't get to the toilet. He had no energy to cook and no appetite to eat anything we took around for him. We tried things to help like moving his living space upstairs, to be near the toilet but then he couldn't get out of the house at all or access food in the fridge downstairs.

56. I asked Steven to consider us both giving up our separate homes and moving in to a bungalow together. The fact that he agreed was a shock to me but an indication that he knew he was in a desperate situation. We set about finding a place and got the key on 1st August 2017.

57. I moved in that day but Steven delayed coming because the internet was not yet connected. I made sure everything was unpacked, set out and cosy to

tempt him and on 5th August 2017 he decided he was moving in the following day.

58. That evening he had a massive heart attack and efforts to insert stents to free the blockage failed and he died in the early hours of Sunday 6th August 2017 at Northern General Hospital in Sheffield.

59. He was gentle, intelligent, generous of heart and witty. He was thrilled to become an uncle when Chris and Emma had [GRO-C] and then [GRO-C] and he is missed, cherished and remembered every single day.

Section 6. Treatment/Care/Support

60. I recall that Steven received some very poor treatment at various hospitals during his early years as a result of his infection with HIV. Plastic cutlery and paper plates were commonplace and everything was thrown away once Steven has used it. Medical staff were always fully gowned when they dealt with Steven. They were terrified of catching HIV.

61. Steven was not allowed to use the local dentist and neither was I due to my Hepatitis B. I used to be a patient at a local dentist practice and I asked if Steven could join and initially they agreed but as soon as I disclosed his HIV status they reversed their decision. A short while later I had to miss an appointment myself due to a Hepatitis B appointment at the hospital. When I next attended my local dentist I was very apologetic and explained the reason why I had not attended and they then told me to find another dental practice.

62. Steven ended up having the majority of his dental care at the Sheffield Children's Hospital and the care he received was not very good. He was not keen to go and they were not keen to receive him.

63. I don't think that the medical practitioners fully appreciated Steven's extremely fragile mental state. He regularly discharged himself from hospital and I believe that his mental health was neglected because no one fully understood

or appreciated the global picture and the terrible burden he had to live with on a daily basis.

Section 7. Financial Assistance

64. Steven received the ex-gratia payment of £20,000 from the HIV Litigation in 1991 and we went to Disneyland in Florida with some of this money. When Steven was aged 5 we were told that he may not reach age 7 and at age 7 we were told he may not reach age 9 and so on. We therefore had a few holidays and rushed to get to Disneyland before Steven's health failed.

65. The rest of the money from the ex-gratia payment was held on trust for Steven by the Queens Bench Master, R Turner, which was used to pay his private school fees from the age of 11 to 13 because he was bullied at the local comprehensive school. I have kept all the letters from the Master, that describes payments he sanctioned and the purpose of them.

66. Steven received the Stage 1 Payment of £20,000 from the Skipton Fund in December 2004 and £3,500 in December 2016. Steven was by that time managing his own affairs.

Steven received payments from the Macfarlane Trust. I have a document sent to Steven from the Macfarlane Trust, dated 24.02.17 which summarises the payments paid to Steven between 16.02.90 and February 2017.

67. I found the application procedure for the Macfarlane Trust relatively straightforward although on occasions it was somewhat protracted given that decisions had to wait for meetings of the Trustees to take place.

68. The Macfarlane Trust paid for Steven's funeral expenses and they also funded the death certificate and probate application costs.

Section 8. Other Issues

69. I was represented in the litigation process back in the early 1990s by Mr Dennis Collins of J Keith Park & Co Solicitors, Claughton House, 39 Barrow Street, St Helens, Merseyside. I signed a waiver/disclaimer agreeing not to take further action, as Steven was a minor at this time. As far as I am aware, Steven has not signed any such a document.
70. I was previously the Chairperson of the Norfolk and Norwich Haemophilia Support Group and I would attend national meetings and later present the information at regional meetings to other members of the local haemophilia support group. I receive a letter almost every day telling me about someone I knew who had died. It was so upsetting that in the end I had to retire from this post.
71. I attended the meeting with the Bishop in London in September 2017 because one of Steven's brothers, Chris, had insisted that I must go. However, it was shortly after Steven had passed away and I was in no fit state of mind to really engage with anything at that time.
72. Steven had had his hopes built up by news of a Public Inquiry and he always hoped that one day the Government would acknowledge their responsibility to the people who had been infected, just like him and provide proper compensation for the suffering they have caused. Their initial failings in knowingly allowing contaminated blood products to be used, their shameful efforts to cover this up, their disgusting handling of the ex-gratia payments with the use of bully tactics and emotional blackmail, in an attempt to get everyone to agree, while some were already dead and others dying was truly horrendous. In addition, I was informed that Legal Aid would be withdrawn if I did not accept the ex-gratia Payment and I was unable to afford to continue to fight. Throughout all of this behaviour the Government were slyly covering their tracks.

73. At the same time the DWP were treating a group of HIV and Hepatitis B and C, infected Haemophiliacs in a disgusting way, making them feel like worthless scroungers, while suffering every single day, beyond the realms of most people's comprehension. They were made to feel like this throughout their miserable lives with the constant threat that they would lose their benefits if they did not jump through the numerous and unnecessary hoops, time and time again.

74. It is anticipated that the inquiry will take between 4 and 6 years to conclude. In the meanwhile, I would call on those in power to show immediate compassion to those like Steven, who are suffering the anxiety and anguish of benefit assessment reviews. This is something that can be done now, to alleviate the additional pain for a few people in the interim period.

Anonymity, disclosure and redaction

75. I do not wish to be anonymous. I recognise that many haemophiliacs and their families, especially those who are still alive, will not wish to be identified. Now that Steven is no longer with us, I feel able to speak out about how this affected him and the rest of our family, on the understanding that nothing can hurt him now. My two other sons and former husband are supportive of me on this and are prepared to deal with any repercussions.

76. I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.

GRO-C

Dated.....

19th March '19 .