

Witness Name: Camilla Dinkel

Statement No: WITN2855001

Exhibits: WITN2855002

Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CAMILLA DINKEL

I, Camilla Dinkel, will say as follows:-

Section 1. Introduction

1. My name is Camilla Dinkel. I was born on GRO-B 1946 and I live at GRO-B
GRO-B
2. I have been living on the west coast of Ireland for the past twenty years where my second husband and I run a bookshop.
3. I make this statement on behalf of my late husband, John Michael Anthony Dinkel. He was born on GRO-C 1942 and died on 15 August 1991, aged 42 as a result of cerebral toxoplasmosis.
4. This witness statement has been prepared without the benefit of access to my late husband's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Infected

5. John suffered from severe haemophilia A. According to his medical records he received Cryoprecipitate, Factor VIII concentrate (FVIII) and Whole Blood between 1969 and 1991 at various Haemophilia Centres. A copy of his National Haemophilia Database which list the products, centres and dates is exhibited at **'WITN2855002'**.
6. I met John in 1969 and we married within three months of our first meeting. He was a man of great charm, with a wicked sense of humour. We lived in **GRO-C** after our marriage, and he attended the Haemophilia Centre at Royal Free Hospital (RFH) in London. His treating doctor was Dr Katharine Dormandy.
7. In or about the early 1970s, we moved to Glasgow where John was employed to run the architectural competition for the Burrell Collection. At that time he would have been treated when necessary with Cryoprecipitate at the Royal Infirmary Hospital (RIH) in Glasgow. I do not have his medical records for that period and cannot say how often this would have occurred. Above all, he wanted a normal life; when it came to starting a family we talked about adoption as John did not want to bring his offspring into the world with haemophilia, but there was no real doubt in our minds that we would go ahead and hope for the best. Our first daughter, Cosima, was born in **GRO-C** in the Queen Mother's Hospital in Glasgow.
8. In 1974 John was appointed Keeper of the Royal Pavilion in Brighton, where our second daughter Sophie was born in 1975. John resumed attendance at the RFH as the Royal Sussex County Hospital (RSCH) was not an official Haemophilia Centre, though it did supply him with FVIII. It was during this period that he went on to home treatment with the freeze dried coagulant called Factorate manufactured by Armour Pharmaceuticals. This was life changing – he could treat himself at home with my help, and to some extent use it prophylactically, though he was always rather reluctant to do so.

Holidays were much easier to organise. We felt self-sufficient and in charge of his condition.

9. John was first diagnosed with HIV at the RFH on 14 September 1984. (His last negative test date was 11 June 1982). I have always assumed that the infection came from the product manufactured by Armour Pharmaceuticals called Factorate, although as is shown above, he received many different products over the course of his life, including complete blood transfusions when he was a baby.
10. I cannot remember being given specific advice or information about the risk of infection from the blood products. John himself had always been aware of the dangers long before the freeze dried concentrate became available. For a severe sufferer there seemed to be no alternative to accepting whatever was on offer, and we did not question its provenance. Once he was confirmed HIV positive obviously we were told about the risks of transmission, and this was one of the most painful things for John and for me. It put an end to our sex life. We were often in a position of having to explain to strangers that HIV is not transmitted on the lip of a mug, something even the hospitals failed to understand, nor by Holy Communion. This message was very hard to put across.
11. RFH confirmed that John was also infected with Hepatitis C (Hep C).
12. In 1984, he applied for a financial product (maybe insurance, or a second mortgage) and had to go for a routine medical examination and blood test. This may have been carried out at our GP's surgery in Brighton. In any case the results came back to our GP showing John to be HIV positive. At the time we had no clear idea of what this might actually mean. I am fairly sure that we attended RFH quite soon after this, and as I have mentioned above, their records show his first positive result was dated 14 September 1984.
13. It is hard to convey now how ignorant and helpless we were in the face of this diagnosis. As to adequate information about how to understand and manage the infection, this was very early days and even the doctors seemed unable to

provide any. We were in the midst of a media furore about AIDS. The stark truth was that there was no cure. At the time it did not occur to any of us that there might have been cover ups, withholding of information or other attempts to conceal the truth by the specialists who had treated him for most of his adult life. That, at least, was my impression at the time and I am anxious that it should not be clouded by hindsight.

Section 3. Other Infections

14. John suffered from Cerebral toxoplasmosis.

Section 4. Consent

15. John said once that he thought his generation of haemophilia sufferers had been written off, and that they were being used for experiment in the search for an effective treatment for HIV. This was his opinion. I have no evidence that he was treated without his knowledge or consent or without being given adequate information.

Section 5. Impact of the Infection

16. I was introduced to John by a friend of his who I worked with (he is now my husband). There seemed nothing wrong with him apart from a slight limp. Gradually I learned that he suffered from haemophilia. It coloured his childhood and his relations with his siblings but of course I did not know him then. His mother devoted herself to his education and to keeping him going during long spells of inactivity. He lost a year at university through hospitalisation, and had surgery on his knee which continued to give him trouble for the rest of his life.

17. John coped very well with his infirmity and I and my daughters took our lead from him in his desire to lead as normal a life as possible. Marriage and family had always been his great desire, along with a job that would suit his education and talents and enable him to support us. All this he achieved through a firmness of purpose and a determination that is no doubt to be found amongst all haemophiliacs not to be defined by the disease. He had

strength and resilience on which we all relied, and a philosophical attitude to life that was a great inspiration. He recovered well from major and minor bleeds.

18. Things changed around his 40th birthday. He suffered increasingly from arthritis, found it harder to get about, and became very depressed. Looking back I attribute this to the inevitable coming to terms with his infirmities which he had put so much energy into overcoming. He was referred for counselling at the haemophilia centre.

19. This is the first time I have tried to articulate the effect on our family of John's HIV diagnosis. Inevitably, it was enormously affected by the connection between HIV and AIDS and its focus on the gay population. There was definitely a stigma attached, very far from the awareness or empathy we find today. It didn't really strike home until he was recovering in hospital from his knee replacement. There was a skull and crossbones on the door of his single room. The cleaner was not allowed in and there were empty blood bags lying on the window sill. He was asked whether he had his own crockery. This was probably the moment at which it became clear to us what we were facing, and indeed I believe that it was the start of great mental anguish for him. The local support services for HIV were excellent, but very much designed for the large gay community. A talk on HIV/AIDS given at my GRO-C daughter's school was prefaced with the observation "of course I don't expect any of you are affected by this". She left the classroom in tears.

20. In May 1990 he went into the RFH for a replacement of his right knee which was causing him increasing problems ever since the patella had been removed during his teens. He recovered well from the operation and his mobility was much improved. In October that year, he suffered a seizure, and was taken to A & E in the RSCH in Brighton. Cerebral toxoplasmosis was diagnosed, and he was put on a terrifying drug called Fansidar, commonly used to treat malaria, which came in a shiny packet featuring a massive black mosquito. I had to unwrap it outside his room. After three months or so a brain scan revealed that the lesion had completely cleared, much to the

surprise of the doctors. However, this was the beginning of the end. He suffered another seizure in May 1991 and died on 15 August that year. The cause of death on his death certificate is given as '1a Cerebral toxomoplasmosis II, Haemophilia'. There was no mention of HIV.

21. There is a huge difference between the way in which terminal illness is talked about today and thirty years ago. Our underlying philosophy was to tackle the moment and keep going, trying as best we could to ensure that John's last days were peaceful and without anxiety. The girls were used to him recovering from bleeds and from surgery over his lifetime and weren't really prepared for him to die. He was able to hang on until he knew that his daughters' immediate future was settled - one at sixth form college, the other at art school. He didn't talk to them about his condition, so nor did I.

22. I gave up my job to look after John during the last two years of his life. During that period he was involved as actively as he could be in the campaign for the government to recognise the plight of haemophiliacs and their families.

Section 6. Treatment/care/support

23. The haemophilia centre offered us counselling and encouraged us to ask questions, which we had great difficulty formulating, and answered them as best they could.

Section 7. Financial Assistance

24. In the last two years of his life John had spent a lot of time and energy on the campaign for compensation. Shortly after he died Mrs Thatcher left office and John Major immediately brought in the offer of financial compensation.

25. As members of the Haemophilia Society we followed and generally supported their campaign for financial recompense, taking their advice about accepting the offer that finally came through after the foundation of the Macfarlane Trust.

26. I signed the letter including the disclaimer that neither I nor any member of my family would seek to bring an action against the National Health Service in the

future. We received £80,000 from the Macfarlane Trust, and there may have been other payments since. I no longer have detailed records. From time to time other benefits have been brought to my attention, most of which I would not have qualified for.

27. I had claimed my husband's life insurance and I receive a widow's pension for life from his employers.

Section 8. Other Issues

28. John was upset and angry at the defensive and obdurate attitude of the Government who to him (and to most of the rest of our two families) appeared to be devoting all their energies to preventing haemophiliacs and any other infected people from bringing a case of negligence against the NHS. Indeed my brother, a journalist on the Financial Times, who wrote a series of articles supporting the haemophiliacs' cause, confirms this attitude; he set up an interview with a civil servant from the Department of Health and his recollection is that the interview was mainly devoted to explaining the dangers of opening the floodgates to other claims. We lobbied our MP, Mrs Thatcher and her various Secretaries of State for Health, one of whom had been a personal friend, but always received the same bland answer.

29. Over the years I became aware that things were very different for other families whose members had received infected blood, and that Hep C was as much of an issue as HIV. I followed news reports from Ireland and France, both of whom seem to have tackled their crisis much more dynamically. But the enormity of the scandal I can truthfully say did not fully strike me until I watched the Panorama programme featuring the campaign by GRO-A.

30. I listened in tears to the evidence given at the outset of this enquiry, and my heart went out to those whose grief is still so understandably present. I realised that we are part of this story. If our version can help achieve the objects of the enquiry we are more than glad to be part of it.

Anonymity, disclosure and redaction

31. NOT RELEVANT

32. I do not want 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 *7 April 2019*