

Witness Name: Anton Rosenfeld

Statement No: WITN3971001

Exhibits: 0

Dated: March 2020

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF ANTON ROSENFELD

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I, Anton Rosenfeld will say as follows:-

#### Section 1. Introduction

1. My name is Anton Rosenfeld. My date of birth is GRO-C 1969 and I live at GRO-C with my partner, Cressida Haughton.
2. I make this statement in relation to my partner's late father, Derek William Haughton who I knew from June 2014 until GRO 2018 when he passed away.
3. Derek was born on the GRO-C 1944 and passed away on the GRO-C 2018, aged 73 as a result of being infected with contaminated blood products. I am writing this statement as I have witnessed his treatment in hospital in the final years of his life, and also the effects it had on his daughter.
4. This witness statement has been prepared without the benefit of access to Derek'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 Affected**

5. I wish to rely on Cressida's statement in relation to this section as she has provided a more detailed account as to how Derek was infected.
6. I was told that Derek had severe Haemophilia B and he was treated with Factor IX (FIX) on various occasions for bleeds. I believe Derek was treated in various hospitals and Haemophilia Centres.
7. As a result of being treated with FIX he was infected Hepatitis C (Hep C) and Hepatitis B. Please refer to Cressida's statement for further information in this regard.

## **Section 3. Other Infections**

8. I believe that Derek received implicated batches of blood which contained vCJD. Please refer to Cressida's statement for more detailed information in relation to this section.

## **Section 4. Consent**

9. I wish to rely on Cressida's statement in relation to this section.

## **Section 5. Impact of the Infection**

10. I wish to rely on part of Cressida's statement in relation to this section.
11. When I first met Derek, he lived an active life, despite his poor health, spending time tending his garden, writing, reading and attending local groups in the village and Coventry. He was a full-time wheelchair user, but he didn't let much stand in his way. I found him engaging to talk to, sharing interests in gardening and politics.
12. His daughter, Cressida, was employed part-time as his personal assistant, five days a week, looking after the house, shopping, cooking meals,

accompanying Derek on hospital visits, and helping to look after the garden. I remember that he was on a low potassium diet because of his very poor kidney function. This made his diet extremely restrictive as many foods contain potassium including many vegetables required for good health. I also thought that it was sad that he couldn't eat a lot of the produce that he grew in his garden.

13. I read the first of his three books he'd written recounting his life as a haemophiliac born in 1944. The book outlined much of the harsh treatment he endured, spending much of his childhood life in hospital. One of the doctor's prognosis was that he wouldn't live beyond 14, which gave him a resolute determination to prove him wrong by a number of orders of magnitude. The account was factual and entertaining and focused on the intricacies of the characters involved, without wallowing in self-pity. I noted that, although there were a number of incidents where Derek knew that he had bleeding in his joints, the doctors refused to acknowledge it, and he was told just to carry on as normal. Sometimes he would have to wait for a few days, until the pain and the swelling became unbearable, before he was taken seriously and admitted to hospital for treatment. This must have resulted in prolonged pain and suffering, and also pointlessly exacerbated the damage to his joints that later resulted in him becoming a wheelchair user in his 50s.

14. The first major health incident that I witnessed was when he was taken into University Hospital, Coventry in December 2016 with pneumonia. He also had atrial fibrillation. I recall him being stationed in a bed in a corridor in A&E for a period of around 17 hours, before finally being transferred to intensive care. During this visit, he informed us that the hospital had attempted to catheterise him against his wishes and without factor cover whilst he was partially sedated. The haemophilia nurse, Kathryn Marshall was very angry when she found out that this had been attempted.

15. Between December 2016 and March 2017 Derek was in and out of hospital five times. It seemed to be the hospital policy to release him before he was fully recovered to finish recuperating at home. I thought that he should not

have been released back home in the frail condition that he was in, especially being an elderly person with many health complications. There is no doubt that the continual emergency admissions and readmissions to hospital must have caused a great deal of stress and taken a toll on his health. In the admission in March 2017 they found intestinal bleeding and carried out a number of investigations until they were satisfied that it had stopped.

16. Luckily there followed a period when he didn't return to hospital for a while. However he suffered breathlessness and struggled to push himself with his wheelchair anything more than a very short distance, which further restricted his independence in terms of going to the local shops or the village hall.
17. In spring 2018 Derek was informed, following tests, that his kidney function had deteriorated and that he would imminently need regular dialysis. In May 2018 he complained a number of times that his feet and legs were swelling to such an extent, that he couldn't put on his shoes. This was a consequence of fluid retention, and he contacted Coventry Hospital to book an urgent appointment for dialysis. The hospital did not respond with any urgency, and Derek reached a stage where fluid was pouring out of his extremely swollen legs and had to drive himself to the hospital, in his sopping wet socks, frightened and angry. Once at hospital he was told there were no available beds and, after refusing to leave, he was admitted and started receiving dialysis treatment. However, treating his health problems was becoming a careful balancing act. The dialysis and his low potassium diet were lowering his blood pressure to dangerously low levels so he was in danger of cardiac arrest. On one occasion, Derek passed out due to extremely low blood pressure because they had taken too much fluid in one go.
18. After this incident, I remember the hospital asking if Derek wanted to be resuscitated in the event of a cardiac arrest. Derek had obviously already considered this and signed a DNR form without too much further thought. This came as a shock to all of us especially his partner, Norma, and his daughter, Cressida. Although Cressida informed me that Derek had said all along this would be his wish as he did not want to end his life existing and

suffering at the mercy of doctors, once it was formalised, it was still a big shock. I remember Cressida leaving Derek's hospital room not long after and we didn't know where she'd gone. She did return but I found out later she'd left the hospital as she was so upset and didn't want her reaction, or what she might say, to upset her Dad. She told me later she'd gone outside for some air and to be alone, as she found it hard to process.

19. The hospital continued to administer dialysis but reduced the duration of the treatment as it was obviously taking a toll on him in his weakened state. Derek also complained about a pain in his abdomen which the hospital continued to monitor. The hospital considered investigative surgery but presumably decided to avoid this due to the associated risks although I do not know the exact details. He was passing malena (blood in his stools) so it was known that he had some form of internal bleeding but they didn't know the cause. Derek's condition improved slightly and, after about 6 weeks, they were considering releasing him. Despite the likelihood that he would need to wear an oxygen mask for much of the time, and need regular dialysis, he was putting those difficulties aside and discussing some of the places he would like to visit on his release. The hospital assured us that his condition was improving and told us he would be released home in a couple of days so we thought that it would be safe to go away for the weekend to Hay-on-Wye as we had a previously arranged commitment there. In hindsight, this was a very poor decision. Due to a mobile network issue we did not receive the message to return to the hospital urgently in time and Derek passed away after receiving two blood transfusions to replace blood from intestinal bleeding. Cressida cannot forgive herself, or the hospital, for feeling it was safe to go away and blames herself for not being there when her Dad needed her the most.

20. The night before Derek died, the hospital started dialysis late at night and he did not get back to his hospital bed until after 1am which had obviously left him in a very weakened state. I think we were all shocked to find this out.

21. The next day, we went to the hospital to collect his belongings. Without any

prior discussion, a nurse appeared from the bottom of the ward corridor wheeling Derek's chair with his soiled belongings bundled into some green bin liners on the seat to take home. I found placing the bin liners of soiled clothes on his wheelchair extremely crass and insensitive. I would have thought that the hospital would have some procedure to discuss his belongings with us first, but it seemed that they didn't have time for this.

22. Coupled with the fact that there is a possibility that Derek had received vCJD implicated batches of blood, soiled clothes, I would have thought, should have been disposed of as a biohazard, not offered for us to take home or at least discussed with us. Further, in light of the vCJD issue, the funeral directors and crematorium should also have been informed of any possible health risks, but this did not happen as far as we are aware. In fact nobody ever mentioned vCJD to any of us, including the coroner.

23. At the moment, Cressida is self-employed and is able to take time to do this, but she admits herself that she has reached a point where she is working on the Inquiry case exclusively. I am worried that she is letting everything else in her life slide. She is not taking any exercise and rarely leaves the house or meets anybody. She is in danger of abandoning her soap making business, and not meeting a major order from a local shop. She has also missed countless opportunities to promote her artwork (through the Coventry – Dresden art exchange, the Coventry Biennial of Contemporary Art and preparations for the Coventry City of Culture in 2021). She also suffers from long term health problems, having frequent migraines that make it difficult for to read and concentrate, and I am concerned that the long hours involved in research, are having an impact on her physical and mental health.

24. Please refer to Cressida's statement in relation what treatment Derek received for the Hep C infection.

25. I recall Derek saying that he would only be treated if his liver function got below a certain level. At the time the doctors didn't consider it serious enough but from what I ascertain there were other symptoms of Hep C not just how it

affects the liver.

26. The effect the infection had on Derek was very difficult. It is very similar to any other dying relative spending a lot of time in hospital. It took a lot out of us having sudden call outs at moment's notice. We were always unsure if we should go on holiday. We did decide to go away as we thought Derek was getting better. We went away for the weekend and he died that weekend so we didn't get to see him.

#### **Section 6. Treatment/care/support**

27. I wish to rely on Cressida's statement in relation to this section.

#### **Section 7. Financial Assistance**

28. Following on from Derek's passing, we had, to of course, organise the funeral and the estate. One major obstacle to this was that the Department of Work and Pensions (DWP) froze all the assets on the estate, pending an investigation into the amounts of benefits he had received. Derek had received ex-gratia payments from the Skipton Fund and the England Infected Blood Support Scheme (EIBSS) and, despite it being clearly stated in law that these payments are not to be considered in any assessments for means-tested benefit payments, the DWP insisted that 'he had more money than he should have' in his accounts. They then went on to carry out a rigorous check on all his bank accounts. This entailed a massive amount of extra paperwork, including sending them bank statements for selected periods for each of his bank accounts, including the ones set up solely to pay his carers and to receive his EIBSS payments. This spanned a 10 year period.

29. In September 2019 the DWP phoned Cressida up without warning, asking what Derek spent his money on for specific transactions from 2014 to 2018. This came at a time when she was snowed under with investigating a mass of medical records sent from Oxford hospital for the Infected Blood Inquiry. The DWP asked Cressida over the phone what her late father had spent £300 of his EIBSS money on. Luckily, Cressida happened to have the bank

statements to hand and was able to eventually provide explanations, but only after a lot of deliberation. How could she possibly be expected to know what he spent his money on? She felt put on the spot and made to feel anxious. Cressida found the whole experience intrusive, extremely distasteful and says it felt like bullying. We could understand them scrutinising his sources of income, but could not see why they had a right to question what he spent his money on. They said it was in case he had invested his money. Cressida asked them to send us a written record of the transactions they had queried, which they did, but strangely they did not include the question on the £300 EIBSS expenditure in the letter. This rather suggests that they were aware they should not have been asking this question, so chose not to keep a record of it. There were three phone calls from them that day and Cressida had the presence of mind to record the last two calls, just in case we may need proof later down the line.

30. More than a year after his death, they have now written to tell us that they have concluded their investigation, that assets were correctly taken into account and that their Inquiry is concluded. The language is vague but we have assumed that this means that they don't expect us to pay anything back to them. It is only through Cressida's thorough record keeping, and researching into the rules and regulations, that we were able to satisfy them. It is clear that the DWP were hoping that, through their bullying approach, we would not be able to provide them with proof that Derek was entitled to the payments he received, so that they would be able to claw back payments from Derek's estate. This greatly added to the amount of work and stress in an already difficult period, took time away from Cressida's case for the Inquiry and also caused complications and delays to our planned house move.

31. Until November 2019, Cressida was in private therapy, costing £60 an hour. This started as charity bereavement counselling but the number of sessions was limited and now we can only afford one session a month. We requested a one off discretionary payment from EIBSS to include the funeral costs and ten counselling sessions. EIBSS paid for the funeral, but refused other costs (including printing the order of service booklets). They refused to pay for



counselling sessions, even though the total sum that we requested was below the upper limit of the grant that was available. We know Derek's partner has also found it difficult accessing financial assistance from EIBSS, mainly in terms of their insistence on her providing various documents.

## **Section 8. Other Issues**

32. Cressida is now spending all her time researching her late father's records and scouring the internet for research papers to try to understand some of the things she has found in Derek's hospital records, to be able to provide evidence for the Infected Blood Inquiry, especially mention of other infections we had no prior knowledge of. She typically works from 9am until the small hours of the morning, only taking an hour's break to eat in the evening. She is doing this in order to achieve justice and to honour her late father. She wants to do the best she can and make sure that nothing is missed. In order to be able to do this fully and satisfactorily, this entails trawling through numerous large boxes of hospital records and reading medical research papers on Hep C and other clotting factor concentrate transmitted viruses, methods of virus inactivation etc, cross referencing batch codes, looking through her father's letters and also his published books. The amount of work is completely overwhelming.

33. Two hospitals have sent a large amount of material and the sheer volume of records to look through is a pile of paper almost 3ft high. Many of the records arrived, not in order, and many are written in virtually illegible handwriting or with crucial details missing. Obtaining these records has not been easy. She had to contact seven hospitals, plus the GP service and UK Haemophilia Centre Organisation. Some hospitals initially replied, saying that they had no record of Derek, and had to be repeatedly contacted before they sent anything, I imagine hoping she would give up. To date we are still waiting for material from some hospitals.

34. Cressida has also tried to encourage other members of the family, her brother Damon, Derek's partner from the 1980s-1990s Julie Moseley and Derek's

partner Norma Jardine and myself into giving statements to the Inquiry. This has not been easy. Cressida's brother is in a vulnerable state and cannot face the situation or talk about it at all, with anyone. He has therefore not made a statement.

**Anonymity, disclosure and redactions**

35. I do not wish to remain anonymous.

36. I do / 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

9<sup>th</sup> March 2020