

Witness Name: K Rendle
Statement No: WITN3372001

Exhibits: 0

Dated: June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF KATIE RENDLE

I, Katie Rendle, will say as follows:-

Section 1. Introduction

1. My name is Katie Rendle (nee Evans) of GRO-C
GRO-C I was born on GRO-C 1980. I live with my husband and we have a 16 month old daughter. I have worked as a freelancer in web content for 20 years.
2. I have prepared this statement in relation to my brother Andrew Evans who was infected with Hepatitis B, Hepatitis C and HIV as a result of receiving contaminated blood products. He has submitted a witness statement to the Inquiry (WITN1213001).
3. This statement has been prepared without the benefit of access to Andrew's full medical records.

Section 2. How Affected

4. My brother, Andrew, suffers from severe Haemophilia A and has received Factor VIII contaminated blood products resulting in being infected with Hepatitis B, Hepatitis C and HIV.
5. Andrew was predominantly treated at Birmingham Children's Hospital.
6. I was aged around 8 or 9 when Andrew told me that he had been infected. One day while we were going somewhere in the car, Andrew said to me in an exaggerated, comical voice "*Don't touch me! I've got AIDS*", mimicking how he was told other people would react to hear the news. Andrew was aged approximately 12 at the time and he let it slip. It forced my parents to have to tell me about Andrew's infection. They told me that I must not tell anyone and that Andrew would most likely die within the next two years. My mum cried.
7. Although I was very young at the time, I know from subsequent conversations at home that my parents' concerns about Factor VIII concentrate were brushed aside and they were strongly advised to continue treatment.
8. I remember that there was a lack of information about HIV at the time. Even as a child, I'd heard of HIV and knew it to be something very terrible, but it was also new. Nobody knew what would happen, but my parents were initially told that Andrew would die within two years.
9. I found out Andrew was also infected with Hepatitis C when I was a teenager. I was not told about any risk of transmission of Hepatitis C. I infer that my parents also did not know. I learned years later that it can be spread more easily than HIV.

Section 3. Other Infections.

10. I refer to Andrew's statement for this information which provides accurate details.

Section 4. Consent.

11. I refer to Andrew's statement for this information.

Section 5. Impact

12. Andrew's infections have transformed every aspect of his life. The life he could have had if not for these infections would be totally unrecognisable to the life he has forged out for himself. From his teenage years to today he has suffered a barrage of debilitating, crippling illnesses and conditions. His potential to live a 'normal', healthy, happy life was stolen. We feel deeply grateful just to have him still alive and with us. The injustice of the life that was robbed from him and from our family haunts us always. Not only does Andrew still battle on against illness that most would find intolerable, but he has also given years of his life to campaigning. Years that are precious to him and to his family as we're always wondering how many he has left.

13. I believe that my parents intended not to tell me about Andrew's HIV diagnosis initially, with a view to shielding me from the harshness and pain. This served to create a sense of isolation for me, which increased in later years.

14. At the time of finding out about Andrew's HIV diagnosis, I tried to take it all in. I had recently moved schools and instead of playing with new friends I would tell them I needed to be alone to think. I would think about death. In my mind at the time this meant imagining gravestones and feeling desperately sad. I thought this might prepare me for when Andrew died (which we believed was imminent).

15. Over the years, I had a hard time forming long-lasting friendships. I rarely confided in people. As a child, I was unable to keep Andrew's illness a secret and I told some close friends who sadly did not understand. They could not relate. I believe they told their parents who then did not want them to be spending time with the sibling of someone with HIV. As a result of Andrew

becoming increasingly ill, my friends started to pull away from me even more. In later years, they told me they could not handle being with me. I imagine I was not very fun company.

16. Living with the secret was very difficult, especially as a young child. I felt like it was a dirty secret in some ways, which people just did not understand. I am still careful about who I confide in to this day.

17. Throughout my GCSEs, Andrew was regularly in and out of hospital as he consistently caught infections. We attended the same high school. He managed to complete his GCSEs but he was unable to finish his A-Levels due to ill-health. He is a genuinely very intelligent person and I think he would have been a doctor, scientist or engineer if he had had an uninfected life. He told me that when he was very ill, the teachers conducted an assembly and told everybody what had happened to him. I was not present at school at the time, but I don't know whether this was deliberate.

18. As I was growing up, I missed out on attention from my parents, which I desperately craved. I spent my childhood wanting to be seen and included. Then, as a teenager when Andrew was mostly in hospital, I tried hard not to be an additional burden. When I was about 13 or 14 years old, I had suicidal thoughts. I remember thinking that the only reason I could not go down that path was that I didn't want to hurt my parents even more. I made an effort not to make it any worse for them.

19. Every time the ambulance was on its way to our home in the middle of the night, I would sit by the window waiting for it while my parents were with Andrew. Then I'd go to school the next day. I had no friends and nobody to confide in. My parents were mostly in the hospital. If I didn't go with them to the hospital, I stayed at home with my grandmother, who lived with us.

20. Everyone in my family has been affected by this scandal. I have vivid memories of my mum sitting at the end of my bed crying. My dad was not an overly emotional person but he suffered. The whole family had nothing like a normal life for several years when Andrew was very ill. We basically lived at

the hospital where my mum made friends with some of the other mums whose kids had cancer (Andrew was placed on the cancer ward). There were many funerals.

21. At one stage, the doctor told us that Andrew had approximately 3 weeks left to live and that we should all make our final preparations. We were not offered any support. I would occasionally break down in tears at school and my mum asked the teachers to make allowances for me. I was allowed to sit in the classroom during break times so I would not have to be alone outside. Other kids found it very strange.

22. On a leap of faith Andrew started a new, experimental treatment for HIV: combination therapy. He started to feel a little better but we had no idea how long it would last. It felt like life in limbo, especially for Andrew. His friends, his education and his life as it was had all moved on. He was very alone for several years and his confidence plummeted.

23. Andrew eventually met someone, fell in love and started to build a life. His partner lived in America. I visited them both and I was elated for him. She was also infected with HIV as a result of contaminated blood products, and had related serious health complications. She became seriously ill very suddenly while they were in the midst of planning their wedding. She died while I was on the flight over to America to support Andrew. I stayed with Andrew for two weeks while we planned and held the funeral.

24. Our father was also very ill in hospital during this time and while I was on the plane home from America, he died. As a result, Andrew had to pack up his life in America in short order and come home too. His life returned to limbo for a while. His resilience shone through somehow.

25. Eventually he met his wife Michelle GRO-C
GRO-C Miraculously, he found someone who could empathise and who truly understood. They have built a lovely life for themselves and they have a wonderful family.

26. Andrew has always wanted to live as normal a life as he could. His potential to live a really normal life was devastated and mine was significantly affected. I do not feel that I had a normal upbringing and I do not feel that I was really *raised* by my parents. I was alone a lot and my world was very small for many years. I spent a lot of time trying to figure out how to have a decent life. I have made a lot of poor decisions, particularly in relationships.

27. I studied Creative Writing at Middlesex University. I attended a university in London in order to get away from my family life. I wanted to be an author since I was a little girl as I used to write short stories and poems. I was cautious with people but I did not realise or accept this until well into my adulthood. I made friends but I did not get a typical social university experience largely due to GRO-D

28. GRO-D

29. When I left university, I worked in a bookshop for a year. I think that I did not have enough life skills to get the kind of job I wanted. I felt quite stuck there and I did not really feel like I could do anything else for a while. It was during this time that Andrew's partner and our father both passed away. After my dad died, I had a fear of not ever getting to live out my goals. I decided to volunteer in Peru for a few months, and see Machu Picchu.

30. When I returned, I found a part-time job with an alumnus of the university I attended. It was great experience but he never paid me. In the end it worked out in my favour, as I got some experience doing the work I do now with web content.

31. Between about 2004/5 and 2010 I was a trustee for a charity who work with siblings of those with life limiting illnesses or disabilities. I had spent my childhood fading into the background because of Andrew's illness and knew how it felt. I felt (and still feel) strongly that siblings in this scenario often get overlooked.

32. I have a daughter now and I plan to teach her to make better life decisions than I did. I definitely intend to give her the love, attention and view of the world that I missed out on.

Section 6. Treatment/Care/Support

33. Please refer to Andrew's statement.

34. I was never offered any counselling.

Section 7. Financial Assistance

35. Please refer to Andrew's statement for his involvement with the Trusts/Schemes.

36. At one point Andrew pointed out to me that there were vacancies for user trustees at the MacFarlane Trust. They intended to represent beneficiaries to the board. He knew I had been a trustee of a charity previously and the reason he wanted me to get involved was because he knew there was dissatisfaction amongst the beneficiaries about how the Trust operated. He thought that I would be quite good at finding out how decisions were being made and trying to improve relations. I was there for a few months and I did see how things worked. I think one of the reasons why I was appointed as a trustee was my background in media communication. My idea was to implement more "*two-way communication*". The main activity I carried out whilst I was there was a survey to beneficiaries regarding how they felt about the way the MacFarlane Trust communicated with them. I drafted the questions requesting feedback in such a way that was open and allowed

genuine, broad feedback. The positive feedback that came back thanked the MacFarlane Trust for giving anything at all. On the other, there were reams of negative feedback and dissatisfaction about beneficiaries living on the breadline, being unable to speak to sympathetic people at the trust and being forced to fill out lengthy forms which made the application process difficult. It was emotional reading.

37. I presented the results of the survey to the Board and wanted to share the results to the beneficiary community. The Chief Executive and Chair (Jan Barlow and Roger Evans) wanted to change my report to reflect the MacFarlane Trust more positively. Shortly after this chain of events, Andrew advised me it would be a good idea for me to step down as the tide of opinion toward the trust was turning.

38. Following this I shared the results of the survey with the Chair of the Partnership Group but I doubt he distributed these further. I believe the Chief Executive and the Chair just looked to shut the whole thing down.

Section 8. Other Issues

39. I hope that there is an admission of culpability. I think acknowledging that there has been a gross mismanagement over many decades would be a huge step forward for everyone who has been touched by this scandal.

40. Most of all I hope there is a package which will support Andrew and his family. I live every day with the thought that Andrew will go prematurely and I would like him to have the security and peace of mind of knowing that his family will be looked after financially when that happens. I would like him to be compensated for what has happened to him, and for the life that was stolen.

Anonymity, disclosure and redaction

41. I do not wish to apply to retain my anonymity and I understand that this witness statement will be published for the purposes of the Inquiry.

42. I would be prepared to give oral evidence to the Inquiry if they felt it was important.

Statement of Truth

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

Signed.....

GRO-C

Dated.....27/06/19.....