

Witness Name: Deirdre Jane Mackey

Statement No: WITN1686001

Exhibits: 0

Dated: December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DEIRDRE JANE MACKEY

I, Deirdre Jane Mackey will say as follows:-

Introduction

1. My name is Deirdre Jane Mackey, my date of birth is GRO-C 1950 and I am 68 years old.
2. I am the mother of Paul Christopher Mackey, who was born on GRO-C 1969. Paul was infected with HIV and Hepatitis C after receiving Factor VIII around the early 1980s.
3. I live at GRO-C with my partner, who is not the biological father of my two children, Paul and Janet. I am currently retired; in the past I have worked in the care industry and for the social services as a cook.

How affected

4. My son Paul suffers from Haemophilia A. His condition is severe enough to cause frequent bleeds in his joints and this resulted in hospital visits from a very young age.

5. When Paul was four years old, he had three teeth extracted at the dentist. The following day, I found him collapsed on our bathroom floor as he lost and swallowed excessive amount of blood. He was rushed to Southport Infirmary, Southport, where he had some tests which confirmed he had Haemophilia.
6. I had not heard of Haemophilia until Paul was diagnosed. Although my mother was a carrier, she did not warn me of this. After Paul diagnoses, it came to light that I am also a carrier.
7. Paul enjoyed reading books, this was because he was not able to participate in much contact sport. My husband at the time, Paul's father, was extremely disappointed by this, he had trouble accepting Paul's illness and that he was unable to carry out activities which most boys Paul's age could. This put a lot of strain on their relationship, as a result, Paul was not close to his father.
8. Paul also missed a lot of school as he was frequently in and out of hospital. He initially received Cryoprecipitate treatment at Southport Infirmary, Southport, and later on at Alder Hey Hospital, Liverpool. Whilst at Southport Infirmary, Paul was under the care of Mr Kirkham. I cannot recall whose care he was under at Alder Hey Hospital.
9. I believe Paul first received Factor VIII sometime in the early 1980's, however, I was not made aware that his treatment was changing from Cryoprecipitate to Factor VIII. Unfortunately, as a result of receiving the Factor VIII, Paul was infected with HIV.
10. Paul was involved in a minor car accident in the early 1990's. He went to the accident and emergency department at Southport Hospital where he was treated very poorly. The hospital staff did not believe that he was a haemophiliac and prescribed him with blood-thinning painkillers and sent him home. A few days after the accident, Paul's leg started to swell and bleed, he returned to the hospital and he was admitted and treated with Factor VIII. I was with Paul at the time. He had some further tests but he was not told what

for, we just thought these were routine tests following on from the accident to make sure his leg is fine.

11. Whilst being treated at the hospital, Paul saw a haematologist called Dr Woodcook, who informed Paul that he is HIV positive. He was in his early 20's at the time of the accident, so this conversation took place sometime in the early 1990's. The haematologist did not discuss the infection in any detail and merely advised Paul to 'stay away from sharp objects'. He gave Paul a booklet on HIV, however, this information was not enough for us to live with what had happened. I only came to find out about Paul's infection after my daughter Janet told me. This was because Paul was too upset to tell me. I was in shock, I had limited knowledge on HIV at the time, but I did know there was a lot of stigma attached to this condition.

12. Paul was also diagnosed with Hepatitis C. However, I have very limited information in relation to this. I am not entirely sure when this was, but it was definitely in the more recent years. I believe this could have been when Paul was diagnosed with tuberculosis around 20 years ago.

13. I am unable to comment any further on the Hepatitis C infection as Paul eventually limited how much he spoke to me in relation to his health.

Other Infections

14. Paul has had tuberculosis (TB) in the past. He had moved to Wales with his wife Collette; however he had to move back to England as the weather was detrimental to his TB.

Consent

15. Paul was unaware he was being tested for HIV. He had no knowledge or information of what he was being tested for. As far as he was aware it was routine check ups.

16. I believe that Paul was tested for research purposes. I recall one time when he had a transfusion at the age 6 at Southport Infirmary, he was hooked to a transfusion machine and I was not informed why.

17. I was not aware that Paul's treatment had changed from Cryoprecipitate to Factor VIII. I do recall the nurse once stating that his treatment was 'very expensive', but I didn't know she was referring to the Factor VIII treatment.

Impact of the Infection

18. The mental impact of the infection on Paul's life was immeasurable, he felt extremely worthless after finding out he had HIV and Hepatitis C.

19. Paul became very reserved and reclusive; he had no desire to socialise with friends and spent a lot of time in his bedroom. I believe the reason for this was because he felt as though he could not speak to anyone without being judged. There was certainly a large stigma attached to Paul's illness which affected us both. I eventually started telling our extended family and friends in an attempt to diminish the shame behind the illness, I tried to break down the ignorance in others by explaining the situation to them, but I could see the reaction on their faces when I did so.

20. Paul went through a rebellious stage of mixing with the wrong crowd of people and started to frequently drink alcohol and smoke cannabis. I believe the main reason for this was frustration and anger.

21. Due to the lack of information Paul had access to at the time he was diagnosed, he believed that he would soon die and used this as an excuse to act out-of-character. I tried helping him as much as I could, however, he kept pushing me away. This hurt very much as not only was I struggling to deal with his reality, I had to witness my son breakdown and there was nothing I could do about it. It made me feel worthless.

22. Paul had a girlfriend called Linda, with whom Paul shared a young daughter with, called Jade. Jade was around 2 years old when Paul was diagnosed with HIV.

23. Paul left Linda and Jade for a few weeks whilst he went traveling to clear his mind. He wanted some alone time. This was not long after he was diagnosed with HIV. This left Linda in complete shock with the entire situation and led to the breakdown of their relationship.

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 Jade is now 28 years old. She has a good relationship with Paul which I believe has helped him cope with his health.

26. Jade is a strong young lady, however, she confided in me once as she lived with worry that her father would not be here for very long.

27. Paul is currently married to a lady named Collette. He met Collette within one year of being diagnosed with HIV, they moved into my home for a short period of time, during this time both Collette and I had to encourage Paul to stay strong and take his medication as he was reluctant to do so.

28. Paul was prescribed around 7 or 8 tablets to take daily. I initially did not have faith in this medication, however I now realise they have helped Paul live with his condition, although it is not without their drawbacks and side-effects.

29. Paul's Haemophilia affected my relationship with my daughter Janet. She often states that Paul is 'my favourite child' due to the time I spent with him.

This sacrificed the time I was able to spend with Janet during her childhood years.

30. Janet was the one to tell me the initial news of Paul's HIV when he was first diagnosed. Last summer we had a conversation which brought to light that she felt I had negative emotions towards her as she was the bearer of this bad news. This is something that had got in the way of mine and Janet's relationship as she felt that I blamed her for Paul's HIV. I wish I could have been there for Janet during her childhood years, but Paul's condition meant that a lot of my time was pre-occupied. I didn't realise this affected Janet as much as it has.

31. Following Paul's HIV diagnosis, I was also tested for the same. As daunting as this was, I almost wished it had been positive so I could have shared some of his frustration and anger. Each time I think back to when I took him to the hospital, it feels as though I was taking a lamb to the slaughter house. The whole experience was horrible. This was my son, my only son, I trusted the hospital to treat his haemophilia and not aggravate his health by treating him with infected blood.

Treatment/care/support

32. Paul had to go to a sexual health clinic to receive the necessary medication to help cope with HIV. This troubled Paul because of the stigma attached, and that he was being treated in a way that assumed he engaged in certain behaviors which was not the case.

33. Neither me or Paul were offered counselling. I wish we were given this option, since it is a lot easier talking to someone that isn't family, and you can express your emotions more freely. I could have benefited from this.

Financial Assistance

34. Paul received money from the Macfarlane Trust over a period of time. I do not know the amount he received.

35. Paul always felt that he was begging for the money, he gave up with the Macfarlane Trust a while ago because he felt they were not treating him adequately.

36. I remember that he had to sign a waiver to say he would not take any further action.

37. I did not receive any financial assistance or money to assist me with Paul's condition.

Other Issues

38. I just hope something positive and constructive comes out of this inquiry. I have been waiting many years for answers; it is the least I deserve.

Anonymity, disclosure and redaction

39. I confirm that I do not wish to apply for anonymity. I understand this statement will be published and disclosed as part of the Inquiry.

40. I am happy to give oral evidence if necessary.

Statement of Truth

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

Signed...

GRO-C

Dated

11/1/2019.