

Witness Name: KAREN MERRY

Statement No: WITN4702001

Exhibits: 0

Dated: October 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF KAREN MERRY

I, Karen Merry, will say as follows:-

Section 1. Introduction

1. My name is Karen Merry. I was born on [GRO-C] 1969 and I live at [GRO-C]
[GRO-C] Surrey [GRO-C]
2. My brother, Jason George Ward (born on [GRO-C] 1968), was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated blood products. Jason died after contracting PCP pneumonia and advancing to AIDS Related Complex (ARC) on 24th July 1990, aged 22.
3. This witness statement has been prepared without the benefit of access to my brother's full medical records.
4. My mother has provided her own Witness Statement to the Inquiry (WITN1590001) and I refer to that from time to time within this Statement.

Section 2. How affected

5. Jason had severe Haemophilia A, diagnosed at birth. He was treated with Cryoprecipitate initially and then Factor VIII (FVIII) concentrate. He was under the care of Dr Bevan at St George's Hospital, Tooting, London (SGH). My parents were not warned of the risk of infection prior to him having treatment.
6. Jason was told that he had HIV In 1983 by Dr Bevan at an appointment at SGH. He was just 15 years old. He was there with my mother as was usual. There was no pre-warning about the appointment and my father was at work, unaware of any cause for concern. I do not think that they were given any advice whatsoever to help them to understand or manage the infection. There were no treatment options under discussion because there was no treatment. HIV was a relatively new thing back then. The prognosis was that Jason would 'probably die' and it was left to our mother to deal with it. She had to come home and tell my father and me. I was then 13 years old. Now that I have children of my own, I can barely imagine what that must have been like for my mother. It was horrendous. There were no answers about how, where or when Jason had become infected.
7. We weren't told how HIV was transmitted. I had no idea at the age of 13 how the infection spread and/or how you could catch it. There was fear, stigma and misinformation about HIV/AIDS as news of the virus emerged in the media. It was thought then that you could catch it from drinking from the same cup. None of it was true but there was no understanding of it back then and it was scary. I have always loved my brother at 100% but I was torn and confused. I hate saying this but, for a short while, I did wonder if I could catch it from something in my own house.
8. We became aware that Jason was also infected with HCV on holiday in the USA years later in April 1990. He became very unwell and turned yellow in

colour. We took him to hospital just before we were due to return home and we were told that it was hepatitis.

Section 3. Other Infections

9. I am not aware of any other infection.

Section 4. Consent

10. Jason was tested for HIV without knowledge and consent. We knew nothing about HIV at all until we were told that Jason had it. We had no idea that Jason had HCV until the doctor in the USA told us so.

Section 5. Impact

11. Jason (J) was in his final year at school and he managed to get through without anyone but his very closest friends knowing. My mother (mum) said that it was best to keep it to ourselves. J was a popular kid and, after he left school, people did begin to find out. I was still there. I became the target of bullies. Some pretty horrific and very nasty stuff was said about my brother to me pretty much on a daily basis. There was a real lack of understanding. Fortunately for me I had a handful of extremely supportive friends around me.
12. J was a handsome boy and he was a funny boy. He loved children. I know that he would have loved to have had a family of his own. He was ultimately denied his life. He had girlfriends and lived with a lovely girl for a short period of time. He always told them about it in advance and it was never easy for him. I remember one particular mother screaming down the phone at my mother 'your son has AIDS, keep your f***ng son away from my daughter.'
13. J and I had a very close relationship with our first cousin Steven (Stevie). He was a couple of years older than J and was also haemophiliac. My mum had a very close relationship with her sister (Stevie's mother). Our two families

were close. We went away on holiday together. Growing up, Stevie, J and I were inseparable. There was always the three of us. We came as three.

14. A year or two after J was told that he had HIV, Stevie was given the same news; that he too had been infected with HIV through contaminated blood products. He was told in the same way as J was given the news, with no information. J dealt with it differently to Stevie. J pretty much got on with it. He courageously told the people he wanted to get close to that he had HIV. He took the view that if people wanted to be around him too they would have to accept it. J didn't know what lay ahead for him. Stevie, on the other hand, wanted to keep a low profile and hide himself away from the world (and never more so after Jason died). He watched J become ill and die knowing that he too would have to go through the same thing. That was very hard for him.

15. J started to become very ill from around the age of 20. He was no longer able to work. I had a full time job working during the day time in a pub in Croydon. Our parents had divorced (having split up when I was 14). Mum had a very good job and was the main breadwinner. Mum sat me down and told me that one of us had to give up work in order to stay at home with J as he couldn't look after himself. She asked me and I agreed to do so. She had to keep her own job and pay the mortgage. We had no practical or financial help and it was all wrong. I claimed a Carers Allowance and that was it. I struggled to care for J and had to give it up towards the end. It was too difficult emotionally and physically and I didn't know what I was doing. AIDS is a horrible deteriorating disease. To watch someone you love suffer that way is unbearable.

16. The last months were particularly bad. J's weight plummeted and he lost his hair. J, Stevie and I had a holiday together in Tenerife in January 1990. I look back at the photos now and can see that J's hair was already thinning. By the time we had our family holiday (Mum, Dad, J and I) in the USA in April, J was in a wheelchair. He couldn't walk far then.

17. Our parents remained close friends after they divorced even though they each had new partners. They had J to think about and bond them. Mum even helped Dad decorate his home when he first moved out. My Dad's drinking had become an intolerable issue for Mum, particularly so after they were told J had been infected with HIV. When J was dying, he told my Dad that he had to stop drinking and look after mum and me. Dad stopped drinking from that day and my parents later got back together and remarried. My brother was brilliant. He was wonderful. He was awesome.

18. Stevie died after developing AIDS a relatively short period of time after J's death. I went to sit with him every day when I finished work. I lived through the same experience twice. Stevie knew what lay ahead for him. He sat through J's funeral and said 'I will be with you soon J'. It was heart breaking. The formerly close relationship between my mum and her sister then broke down. My aunt did not deal with the stress of her son's death well and the two sisters drifted apart.

19. My life would have been different had this not happened. I was the top of my class at school. I did not fulfil the potential I had until much later in my life. I now work in paediatrics and love my job but I lost myself for a long time and feel I needed to. I went off the rails. I turned to drink and drugs, looking for a high at weekends. It numbed everything for me. I have blocked a lot out as a coping mechanism and cannot now recall everything as clearly as I once did. People assume that I am an only child. When I explain to them that I had a brother and that he had AIDS and died, they are shocked. There is still some stigma associated with it today. I feel the need to explain how J was infected with HIV. It should never have happened.

Section 6. Treatment/Care/Support

20. Jason went without treatment for HIV and HCV. Jason received all his care through SGH including his dental care. We were not offered any counselling and/or support.

Section 7. Financial Assistance

21. I refer to my mother's Statement except to say that my recollection is that the MacFarlane Trust payment of what I remember to be £23,000 was paid out after Jason's death. I seem to remember Jason receiving a sum of money prior to that. The first payment paid for our holiday in the USA and a few bits and pieces Jason needed.

Anonymity, disclosure and redaction

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

Statement of Truth

I believe that the facts stated in this Witness Statement are true.

Signed.....KAREN MERRY.....

Karen Merry

Dated: 28TH OCTOBER 2020