

Witness Name: J H Stone
Statement No: WITN4112001
Exhibits: 0
Dated: March 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JADE HEATHER STONE

I, Jade Heather Stone nee' Barnes-Mackey will say as follows: -

Section 1. Introduction

My name is Jade Heather Stone previously known as Barnes-Mackey. I was born on [GRO-C] [GRO-C] 1991 and I live at [GRO-C]

I make this statement as an affected daughter of my father, Paul Christopher Mackey, who was born on [GRO-C] 1969 with Haemophilia and was consequently infected with both HIV and Hepatitis C via contaminated blood products. He has provided a witness statement to the Inquiry under witness number WITN1360001.

This witness statement has been prepared without the benefit of access to my father's medical records.

Section 2. How Affected

My father has mild Haemophilia A for which he has been treated with Factor VIII concentrates throughout his life

I refer to my father's witness statement for further information in relation to this section.

Section 3. Other Infections

I believe my father suffered with and cleared Hepatitis C in 1980 as a result of being infected with contaminated blood products.

I refer to my father's witness statement for further information in relation to this section,

Section 4. Consent

I refer to my father's witness statement.

Section 5. Impact

My father is an artist and musician; he also and makes violins and collects vinyl records.

He is a strong willed and determined person and although he is unable to work, he endeavours to stay creative and productive. My father has never allowed his infections to define him, however it would be fair to say it hasn't been easy to pursue a life that has been altered due to the infection.

Growing up, I was obviously aware that my father had an illness and although I cannot remember specifically when I was told, i can recall conversations with my Mother and Grandmother who I believe explained to me that my father had been infected with HIV, however my understanding of it at that time was limited. I remember being quite confused and scared as a child and spent many nights crying myself to sleep as I was convinced of the possibility he could pass away at any time, which was quite traumatic for me.

My mother and father separated when I was relatively young, I believe his diagnosis was partly responsible for this. I believe my mother struggled with my fathers diagnosis and unfortunately this led to a volatile breakdown in their relationship and many years of emotional turbulence and resentment followed this: GRO-D and a lot of me being pulled in different directions trying to make sense of it all. I spent the majority of time with my mother in those early years and was allowed to visit my father once every two weeks. When I did visit my father, I feel he must have made a stellar effort to ensure that I wouldn't be affected by his ill health. This was a real credit to him and an example of his wonderful strength of character. I believe he has always tried to protect and shield me from the realities of his infections, although had I been able to visit him more often, I believe I would have undoubtedly witnessed a lot more. I have always just felt powerless but I suppose I just accepted it and that is how it was.

My father and I never directly spoke about his illness that I can remember, until I was older it was something that was relatively unspoken between us, however I know he was always aware that I knew. He is a proud man and preferred to keep his health problems private and would never really let on if he felt poorly or exhausted.

I was always conscious of my father's infection was but it was only as I became older that I learned more about how the illness has actually affected him both physically and mentally which was very upsetting for me and difficult to process. I am now aged 28 and have had more in-depth conversations with my father about his infections and he has been much more open with me and able to discuss things with the advent of the Inquiry. I have found hearing about his story and struggles extremely shocking as I had never appreciated the magnitude of suffering which my father has endured.

It was especially prevalent when he contracted vole tuberculosis in 1999 – I was eight. I noticed he was very ill at this time – I assumed it was due to the HIV infection, however the reality was that due to the ill treatment he has endured over the years by the medical industry he had developed a genuine anxiety and fear of being hospitalised and so he tried to avoid it, however, eventually he was hospitalised and diagnosed with Tuberculosis. I was then tested for TB and given my immunisation early. My father conquered TB and is very lucky to be

alive but it is important to remember that if his immune system wasn't already compromised due to being infected with HIV he may never have had to.

I have been very open and honest with people about my father's infections and told close friends. I have never personally experienced any stigma from my openness. I found that people were both understanding and sympathetic, however I think that on the most part people were so uneducated about it that they did not realise such a thing could happen and it wasn't until I was older that I learned more of the uneducated and ignorant views held by society in general, with regard to HIV sufferers.

I am particularly saddened and sickened by the fact that those with HIV, including my father, are completely ostracised by society. I refer to the behaviour of both paramedics and ambulance crew as detailed in Section 6 of my statement.

Such behaviour makes my father feel angry and disappointed but he manages to remain resolutely strong. He has understandably struggled to overcome his struggles with his illness privately but has been able to find ways to cope. He now follows the Krisna movement and I believe has made a profound difference to my father's life.

My father, over the years has had to take a lot of medication, some of which had undesirable side effects. He has now been on the same medication since 2001 that seems to work well for him, which is a relief. However, my father has recently been diagnosed with Squamous cell cancer after he developed a swelling on the back of his neck and after numerous, once again disappointing hospital visits, this was finally investigated and he will begin his Cancer treatment in due course. This also highlights the fact that there are a number of ailments and serious health concerns which can arise from the HIV infection. There is always a worry that my father will have to deal with numerous further health issues which do not come with any guarantees.

I have always admired my father and I desperately wanted to see and spend time with him. I put my father on a pedestal and still do and I am grateful to have had him for as long as I have, but I am also aware that I shouldn't have to feel any more grateful than any other child but because of government and medical negligence, I have had to live a life on edge but although I worry a lot about my Dad, I try to remain positive and admire the way he has dealt with matters, with his resilience and strong mindedness. I am proud and grateful of the fact that I have such a good relationship and strong bond with him.

I feel very lucky that I still have my father today and I have tried to adopt some of his positive, awe inspiring resilience.

Section 6. Treatment/care/support

My father was treated terribly by both paramedics and ambulance crew. He had a number of bad bleeds which were extremely serious. However, due to his HIV, those very people who were supposed to help my father, refused to touch him and instead left him in an compromising position.

The above is just one of many bad experiences, as unfortunately on the majority of occasions he attends hospital the visit is largely stressful and disappointing. Clinicians and, in particular, those from Accident & Emergency Departments, simply don't have the knowledge

to deal with his Hemophilia or his HIV. This is a worrying and upsetting fact for my father and his family.

However, I am aware that he is happy with his current consultant who is based at a hospital in Wales.

My father naturally cleared his Hepatitis C before he was even aware that he had been infected with the same.

As far as I am aware my father was not given any counseling or psychological support in consequence of his infections. I have never been offered anything like this either.

Section 7. Financial Assistance

My father and I never really discussed finances or financial assistance so I refer to his witness statement in this regard. However, I am aware that he was forced to sign a waiver in relation to the 1991 HIV Litigation.

With the Inquiry underway and the raising of public awareness as to the magnitude of this scandal, I am hopeful that waivers and "brushing things under the carpet" will be things of the past. This Government will not be allowed to get away with things in the way that previous Governments were able to.

Section 8. Other Issues

I want this Inquiry to ensure that people are held to account and that those affected are compensated although many have already lost family members and no amount of 'justice' will make up for that.

The infections have done untold damage to my father's life and those responsible have got away with their shameful actions for too long; consequences need to be actioned.

I believe that there are people out there who should be going to prison for what they did and there needs to be reassurance that a disgraceful act like this will never be allowed to happen again.

Anonymity

I do not want to apply for anonymity and I wish 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.... 14 / 04 / 2020