

Witness Name: Robert Derek-
Ryan
Statement No:WITN2608001
Dated: 26th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ROBERT DEREK-RYAN

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Robert Derek-Ryan, will say as follows:-

1.Introduction

1. My name is Robert Derek-Ryan. My date of birth is 1981 and my address is known to the Inquiry.
2. I was born with hepatitis B (HBV) in 1981. My mother, Laura Megan Ryan, was given infected blood products while she was pregnant with me.

2.How Infected

1. I was born with hepatitis B (HBV) in 1981, but I wasn't told about my condition until I was 18 years old. I was never given any blood products, so I must have contracted it through my mother, as she was given blood transfusions while she was pregnant with me. There is no record of the hepatitis B (HBV) on my medical records. It was determined that I had it from birth as my Alanine Aminotransferase (ALT) levels were high, around 651 when it should be between 1 and 50.

2. I only found out about my condition at Middlesbrough General Hospital (MGH) in North Yorkshire in 1999. It came to light when my mother changed her GP, who noticed from her records that she had been given contaminated blood back in the 1980's and he advised I should have a test to see whether I had also been infected.
3. I started seeing the consultant at MGH, but as I was only 18 years old at the time, I didn't understand the information I was given. I wasn't given information about the risk of infection to others, I was aware that my condition could be sexually transmitted and spread by blood contact, but besides this not a lot else. When I look back, I think that this information was not adequate, as it was too much to take in at the time. I probably needed to be talked to slowly and not all the information at once.
4. I think I should have been given the information earlier, as I could have been immunised at birth. I'm angry with the whole process, such as not being told when i was younger I had hepatitis B (HBV) when they knew, the fact that the doctors admitted they knew about the infected blood products and let it carry on. They got blood from prisoners and the Government paid off people to keep quiet about it. They knew what they were doing and yet did nothing, there was a test to check for hepatitis B (HBV) at the time, but I was never even offered it.

3.Other infections

1. I do not suffer from any other infections as a result of being given infected blood products. I have been tested to see if I have any other infections and they have all come back negative.

4.Consent

1. I do not believe I have been tested without my knowledge or consent or for the purposes of research.

5. Impact

1. The mental effects of my condition are quite severe, but I find it very difficult to talk about. I always keep it to myself and bottled up. It's always in the back of my mind. I have a slight rash on my face which has gotten worse over the years. It may not be linked to my hepatitis B (HBV), but I am unsure as I have no information on it. It flares up and when I touch it, it feels as hot as an iron. I only discovered a few weeks ago there is a chance it may be linked to my hepatitis B (HBV), but until I see my doctor about it, I can't be sure. I haven't suffered any other physical conditions, but it is very likely I could develop jaundice, cirrhosis and liver cancer due to my hepatitis B (HBV).
2. I had treatment for hepatitis B (HBV) from 1999 to 2000. I was given Interferon Alfa for 3 or 6 months, I'm not entirely sure, but I had to self-inject three times a week in this time and I had to go on sick leave for work for 6 months. The side effects were horrendous. I was told to medicate at night, in case I managed to sleep through the worst of it. It felt like I had severe flu, I felt freezing, but I was boiling to touch. I got up three times a night to have warm baths because I felt so ill, and then when I got up in the morning, I was tired from being up the night before. I have had two liver biopsies, one at MGH and one at Northallerton Hospital, which didn't show any scarring or crystallisation on my liver. I was recommended other treatment, including Tenofovir and other kind of Interferon, but as they can damage the liver, I didn't want to try them as the hepatitis B (HBV) is already damaging my liver.
3. I've never had any obstacles in accessing treatment, but when it comes to care and support it depends how you look at it. I don't know much about my condition, so I haven't had the support I maybe should have had. I've never had any difficulty in accessing medical or dental care.
4. My condition hasn't really had an impact on my social and private life, as I have kept it to myself. I have told some of my friends and they're OK with it. There hasn't been much of an impact on my other family members,

besides when I was on Interferon, and I would wake my parents up in the night but that's it. There hasn't been much of a mental impact on my family and social life, but it is always in the back of my mind, I just don't say anything, it makes me feel dirty knowing I have something that is infectious. There has been no impact on me or my family as a result of stigma associated with my condition.

5. There haven't been any educational effects as a result of my conditions, or any work-related effects besides the 6 months I had to take off work when I was having my Interferon treatment. There weren't any financial effects, my mum did move to be closer to me and gave up her job, and there is the cost of travelling to the doctors, but nothing significant.

6. Treatment/Care Support

1. I haven't had any difficulty in accessing treatment as a result of my condition, but when it comes to care and support, it again depends how you look at it. I have never been offered any support, but then again is there any need to? I'm still in the dark about my condition. I think that more focus is given to people with hepatitis C (HCV) as it is more life threatening. It's also easier to test for and there is not much information for hepatitis B (HBV). I have found it much more helpful to speak to Paul Desmond, the CEO of the Hepatitis B Positive Trust, than my own GP.
2. I don't think this is the fault of the GP, I think they don't know as much, but whenever I go it's always a case of being referred to my Consultant. My Consultant tries to help, but I remember the first Consultant I ever saw was Dr Brendan McCarron, who was a lead figure in the infected diseases field at the time at South James Cook Hospital, as MGH closed in 2007. He was helpful but looking back what he said to me would be like me talking to my 8-year-old. I felt bombarded and I didn't understand what was being said.

3. I have never been offered counselling. I think that at the time I found out it should have been offered to me, but not now as I have lived with it for 20 years GRO-C so it wouldn't do us much good. It would be pointless and a waste of time and money, I would say anyone who finds out they are infected should be offered it, but not me.

7.Financial Assistance

1. I have never received any financial assistance from any Trusts or Funds. I did start to look into it, but only people who are suffering from hepatitis C (HCV) get it. If you suffer from hepatitis B (HBV), then you don't. I think that financial assistance should be available to me. Down the line, I don't know what will happen to me as there is no cure for hepatitis B (HBV). I received a letter in 2016 telling me that I could end up taking tablets for the rest of my life, which I don't want to do as I hate taking tablets, if I need a paracetamol my wife has to literally force me to take it, and I would also forget to take them. No one has ever applied for financial assistance on my behalf, and I am not aware of any other assistance which may be available to me.

8.Other Issues

1. I have never taken part in any other litigation in relation to infected blood products. I am not sure if I have any other relevant documents besides the ones I have already sent to Watkins and Gunn Solicitors, and I have previously done another statement for the Infected Blood Inquiry directly.
2. I did have some issue obtaining copies of my hospital records. I requested it for two months, I completed the form I had been sent, and then I was told it had been sent to my solicitor. When I asked why they hadn't been sent to me, I was told I needed to complete the form, which I already had. I still haven't received a response from them. I eventually got my copies from my solicitor.

Statement of Truth

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

Signature GRO-C

Dated 26/2/2019