

Witness Name: Sion Rhys Thomas
Statement No: WITN2563001
Dated: 18th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SION RHYS THOMAS

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, Sion Rhys Thomas, will say as follows:-

1.Introduction

1. My name is Sion Rhys Thomas. My date of birth is [GRO-C] 1973 and my address is known to the Inquiry. I am married to Alaw and we have 3 kids: [GRO-C], [GRO-C], and [GRO-C] who are 9, 6 and 4. I work as a Civil Engineer and we live in [GRO-C].

2. I intend to talk about my Father, Christopher Thomas, who was diagnosed with HIV in 1984 and died in 1990. I will also discuss the huge impact it has had on our family.

2.How Infected

1. In 1984, when I was 11, my Dad was told he was HIV positive. He was infected by contaminated blood products. My Dad was a Type A haemophiliac, but the severity of the condition was only mild. When I was very young my Dad received Cryoprecipitate. Although once it was approved for use, the blood product I mostly remember him receiving was called Factor VIII. It was like a revolution after it came in. It allowed him to take his medication with him on holiday and meant he didn't have to worry as much about doing the activities he wanted to do.
2. My Dad's leg was amputated at the hip in his early 20's, so it was quite a big amputation. The prosthetic leg was very heavy; I think it was made out aluminium and very unlike what you would have nowadays. The stump socket was huge so when we went on holiday it was like we were bringing a coffin with us. As a kid it was great for playing Dracula.
3. I was aware he used to go to Ysbyty Gwynedd in Bangor for transfusions and treatment whenever he had a bleed. He broke his leg once and ended up in Bangor Hospital (Ysbyty Gwynedd). He would have received Factor VIII at that time. Prior to this he was treated in Caernarfon & Anglesey (C&A) Hospital in Bangor but that has since closed down. I'm not aware over what period of time he became infected by the blood products, but he was told he was HIV positive in 1984. I was only a child at the time of his treatments and I never went with him, so I don't know if he was ever told of the possible risks of infection from them.
4. Myself and my Sister (Rachel McGuinness) were sat down and my Mum (Judith Thomas) and Dad tried to explain in the softest way possible that he had been infected. They told us the news wasn't great but tried to reassure

us that his death wasn't imminent. They didn't give too many details, but they told us not to worry about it just yet. However, we knew that could change in the future.

5. I don't know who informed Dad that he was HIV positive, the way he was told or if he was told about the risk of infection. I don't know what information was given to him about managing the infection. Although at the time even the official information wasn't particularly accurate. A lot of the information that our parents were given, they passed on to us. They told us that we couldn't use the same towels as our Father and toothbrushes had to be kept separate, things like that. After a while that wasn't strictly enforced, but I'm not sure at what point it changed. I don't know if information should have been provided to him earlier. I don't really know much about that side of it as I was only young. However, if there was a chance that he could have been told earlier and he wasn't then that is shocking.

3.Other infections

1. I don't believe my Dad was infected with anything other than HIV as a result of being given infected blood products.

4.Consent

1. I have no idea if my Dad was ever tested without his knowledge or consent. I also don't know if he would have been provided with full information about the risks before each treatment.

5.Impact

1. After my Dad was diagnosed, we witnessed some emotional outbursts from him which were borne from frustration. He was quite a fiery character anyway, but they became a lot more frequent. He would cry, and this was totally out of character for him, I had never seen him cry before. My Dad had

real sadness at the prospect of not being around to watch his kids grow up and watch them have children of their own.

2. The physical effects on my Dad were obvious to see. He became very weak and lost a lot of weight. He was about 16 stone when he was first diagnosed but was only 7 stone when he died. This change happened from the age of 40 to 46. Other than his haemophilia he was pretty fit. Before he was diagnosed, he was very rarely ill and a little while after diagnosis he just seemed to have an on-going cold. He had diarrhoea and became very weak. He would also get ulcers which I'm guessing was part of an autoimmune disease. He was not able to do the stuff that he would have normally done. He used to be very active, he would fix cars, he would rebuild boats, mow the grass and he even created a croquet lawn in the field. My Dad was on a lot of medication. It was probably 7-10 tablets per dose. Keeping track of it all was a bit of a mission so he used to have an alarm and boxes to remind him when and what medications to take. I think he started on AZT around 1986/87. There were fewer drugs for him to take as they combined some of them into one tablet but there was still a lot of medication. As far as I am aware my Dad never faced any difficulties or obstacles in accessing treatment. I'm also not aware if there were ever any treatments that he should have been given which were not made available to him.
3. He definitely suffered from a loss of dignity. In the last two years of his life he had to use cutlery with big plastic handles because his nerve endings were damaged which meant he couldn't hold things properly. He also had to have a drinking mug which had a spout on it. He started to spend most of his time in bed and it must have started before I went to college at 16 because I remember I used to play basketball on the concrete in the garden and it used to drive him potty.
4. As it was over such a long period of time, I haven't got anything different to measure it against. We don't really know what we would have done over that period had he been fit and never became infected. It's hard to measure the impact, although in hindsight you start to think about it more. The first half of

those six years wasn't a period of huge impact. Yes, there was frustration, sadness and anger but that was partly hidden from us. Halfway through the six years it very noticeably changed. You got used to how things were; it became part of normal life.

5. Dad became a lot less social. We always used to have BBQ's in the summer, where people would come around and he held firework parties but all that stopped. The whole thing was a very heavy burden to carry around constantly. We kept it to ourselves mostly and didn't tell anybody about it other than family.
6. In the early days after diagnosis there was no real physical impact on myself or my Sister. I coped mentally although I think a lot was kept from me. I didn't tell any friends at school. At the time there was quite a lot of negative media around and I would hear jokes about HIV in the playground. People knew in the family about the situation, but I chose not to discuss it as I didn't want to talk about how I was feeling. It was just something we lived with. I would lift my Father into the bath and onto his commode. When other family members came to visit, they would find it hard seeing 14 and 15-year-olds helping their dying Father and found it quite emotional. They would struggle with that as they weren't used to it, but we coped alright as it was just part of a normal day for us.
7. When I was around 12, sometimes after doing chores my Dad would take me to the Sportsman for lunch at the weekend. I remember he would give me 20p to play pool. You would hear people mentioning HIV and AIDS in the pub so I was aware of the stigma surrounding it. They obviously didn't know at the time that my Dad had HIV. I was never forbidden to tell people of my Dad's HIV status, but I never really did. I still bump into my Dad's old mates and they always ask about him and want to talk about him. He was very popular and well loved.

8. Although I was fine for the bulk of the time, I would have a meltdown occasionally and then I would just crack on again. It was what it was, so I don't have anything to measure it against. I'm sure life would have been better if he wasn't ill, but who knows for sure. I think I would have benefited from a firmer hand when I was between the ages of 15-17. At the time Dad was too weak to discipline me properly and I probably needed it. I think if my Dad wasn't ill, I would have done my A-levels in school and I would have continued playing rugby. Instead I moved to **GRO-C** to go to the Tech and I stopped with the rugby. My Dad loved rugby and I don't think I would have got away with not playing it. He couldn't take me to the matches at the weekends so that had an impact on my sporting commitments.
9. Initially, Mum was really anxious, sad and **GRO-C** although she kept it well hidden from us. Anyone would be worried about losing their partner. It's someone who you share everything with and you struggle to know how you are going to cope without that person in your life. She was faced with bringing up her children on her own. She became a fulltime carer at the end but she just got on with it. She had her good friend Marian whom she is very close to and she helped mum a lot.
10. Mum was pretty tough throughout it all, and I think my Sister and I followed her lead. My Aunt Ruth who was Dad's Sister looked after me very well. Mum's friend Marian also supported us really well, she would feed us, and we would stay at her house a lot of the time. She really cared for us.
11. It impacted the whole family. Dad's sisters were very sad. My Grandparents were devastated about losing their son; no one is meant to outlive their kids. They had already suffered enough with him having haemophilia and losing his leg. He was the first haemophiliac to have an amputation so that was traumatic enough. They were used to that level of difficulty but having to go through the whole HIV thing was tough on them. Mums' brother John was devastated, he used to look up to Dad as he treated him as a grown up. He used to spend a lot of summers here with my Dad. It was difficult to for my Mums' twin sister as they had an extra special relationship.

12. My Mum had to give up work to look after Dad, so that had an impact on them financially. They had all this going on, but they still had to pay the mortgage and all the bills. My Dad used to tutor and would teach English to pupils by giving them extra lessons. He would also do some public speaking for the Rugby Club. This all had to stop after he became ill so it had an effect on him financially and socially as he liked to do these things. Even though he was retired he would still have many things to do. He would cut down trees for people; he would store caravans at the house. In fact, he would do anything at all.

13. At the time, it was probably preferred for me to go to the Tech in GRO-C so that I would be away from everyday life, to give me more protection from it I suppose. It was at the same time my Sister went away to college. I think it was so I didn't become a carer for my Dad, although I would come home at the weekend and still be like a carer for Dad. In my case, I could have probably done with a bit of a kick to do better in my GCSE's. I think it would have sent me on a different path. Going to Tech probably wasn't the best move for me in hindsight. Being away from home at the age of 16 and having a sick Father was difficult. Just after he died, I was young and foolish, and I had too much of a free reign. I was eleven when my Dad was diagnosed so my whole school life was influenced by it one way or another. It was an important time in my life. Although six years is a relatively short period of time, a lot happened with those years. As I was so young I believe I was protected from a lot of what went on by my parents.

14. It is very difficult knowing that my Father has never been able to meet my children. I tend to not think about it too much, but I do occasionally when I am on my own. It's not until you start to talk about it in this situation, for the witness statement, that you come to realise what the loss means. It's not just my loss but my children's loss too, who will ever get to meet their Grandfather. They do have three fantastic grandparents, so all things considered they are very lucky.

6.Treatment/Care Support

1. I'm not aware of my Dad ever having any problems in receiving any treatment or support after his diagnosis. I also don't ever remember being offered any counselling or psychological help of any kind.

7.Financial Assistance

1. As my Dad only had one leg, occasionally after a bleed he would come home from the hospital in a wheelchair, so we were used to seeing him with one. I remember going in it and being quite proud of myself that I could go around the house on the two back wheels. I think my parents received a grant (although I'm not quite sure who from) for new doors and windows so that it would be more accessible for my Dad. In hindsight if someone came to your house to widen the doors because your Father would be in a wheelchair for the rest of his life it probably should have worried us. However, I never really thought that much of it at the time, other than wondering why we had never done it before, especially because my Dad was so practically minded.
2. I'm not sure if my Dad received any financial assistance from the trusts. I'm aware that my Mum did following his death, but I don't have any information on that.
3. I received £8,000 about a year after my Father died; I believe it was from The MacFarlane Trust. It was years later that I found out I should have received £9,000 and my Sister £7,000 but my Mum thought that it was best that it be split equally. I think the reason they offered me more was because I was under the age of 18 and maybe thought I would need it more. We were skint at the time, so the money came in handy.
4. I'm not aware of the process involved with applying for financial assistance from the trusts or how my mum became aware of them.

8. Other Issues

1. I don't have any further issue that I would like to discuss.

Statement of Truth

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

Signed.....

GRO-C

Dated..... 18-02-2019.....