

Witness Name: Rachel McGuinness  
Statement No: WITN2509001  
Dated: 18<sup>th</sup> February 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF RACHEL SIAN MCGUINNESS

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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, Rachel McGuinness, will say as follows:-

#### 1.Introduction

1. My name is Rachel McGuinness. My date of birth is [GRO-C] 1971 and my address is known to the Inquiry. I am married to Thomas and I have two children; [GRO-C] who is 16 and [GRO-C] who is 14. I work as a fulltime school teacher. [GRO-C]
2. I intend to talk about my Father, Christopher Thomas, who was infected with HIV and died in 1990. I will discuss the impact this has had on our whole family

## 2.How Infected

1. Chris Thomas is my Father; he was a haemophiliac who was infected through a blood transfusion. He had his HIV positive diagnosis in 1984 when I was 13 and passed away in 1990. GRO-C

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2. My Dad was a mild haemophiliac and throughout my childhood he had some periods of treatment. We were quite an active family where we did a lot of water sports and we had a very nice lifestyle. I don't really remember it as such, but I know he would have a treatment called Cryoprecipitate. I mostly remember him having Factor VIII. When it was changed over it meant that he could self-medicate, and we could travel on our big holiday to Canada. It also enabled him to take part in all the activities he wanted to. That was the first time he self-medicated because previous to that he would have had to go to hospital. He had to have special permission to take the medication with him. As we were travelling to Canada there was lots of paperwork, and although Mum and Dad sorted it all out, it appeared to be quite a big thing within the family. We had to keep the medication in the fridge.
3. My Dad was under Dr Korn in Ysbyty Gwynedd in Bangor and I know that he did have some links with the Haemophilia Centre in Cardiff (University Hospital of Wales) with Professor Bloom. I don't know what dates he would have been given the infected blood, all I know is that he was diagnosed in February 1984. I know in his medical file there are records of him being treated leading up to that date in Ysbyty Gwynedd. Prior to this, he also went to C & A hospital in Bangor, but that has closed now. It amalgamated into Ysbyty Gwynedd but I'm not sure what year that was. I was quite young when he was having his treatments, so I don't know if he was ever given information about the risk of being exposed to infection before he had his treatment. He contracted HIV but as far as I am aware there is no mention in his medical records of him being infected with hepatitis.

4. My Dad found out from a test he was HIV positive, but I wasn't party to that information at the time. Mum and Dad shared this with my brother (Sion Thomas) and I quite soon after due to the impact it would have on us. It also meant there would be a change in the way the family household would be run. They had to make sure no cross contamination would happen. In those days they weren't 100% sure how it was passed from person to person. They knew it was through bodily fluids, but they didn't know how at risk we were. I remember them saying to me, that on a scale of 1 -10 we were currently only on a 1 at that time. This referred to how ill my Father was. He got progressively worse over the six year period until his death but for some reason I never thought we had moved away from the 1. I suppose it was a form of denial.
5. I don't know who told my Dad he was infected with HIV or what information they gave him following that. They must have given my parents some advice because we had a change in lifestyle after that. A dishwasher was bought in case any germs were passed to us, and we were specifically told not to share towels. We had to have high standards of hygiene in the house. We were also told how we had to keep toothbrushes separate.
6. My Dad used to think there were some grave issues with what had gone on and he thought that the Government policies had led to his infection. He thought action should have been taken sooner to ensure that the blood products were kept clean. He was quite cross about that. Other than that, I don't know how much he was told but I think information appeared to be patchy. I don't know how my Dad was told about being infected, but I do know my Mum was with him at the time.

### 3. Other infections

1. I don't think my Dad received any infection other than HIV through infected blood products.

#### 4.Consent

1. I don't know if he was ever treated for research purposes or if he was ever treated without his knowledge or consent at any time.

#### 5.Impact

1. I think that in the initial stages, he was really quite angry about the situation. He felt that his life was being taken away from him - which it was. He had emotional outbursts and he was very intense. He was very, very sad, and would cry. I had never seen him cry before that, it was so unlike him. The outbursts and crying happened in the initial stages after diagnosis. Afterwards, when he became more ill, he reacted more emotionally to things. I don't know if it was because he was bedridden so had more time to think about things. Towards the end of his life, there was emotional sadness because he was going to die. This was different to the sadness he had initially, that sadness was more anger and frustration based.
2. In the early days, he had minor ailments, flu symptoms, colds and ulcers; before that he was never really ill. We have a photo of him the first time he was really ill, he seemed to have an on-going cold or flu. Looking back this was probably the beginning of the virus taking hold of him. This must have been around 1985, after he was diagnosed. After this he became much more ill and he lost loads of weight. He had diarrhoea and he used to be on the toilet all of the time. I think this led to him having a fissure and he had to be treated for this which meant it was a further complication. He would also have additional infections and muscle weakness which led to being bedridden. In the latter stages he had more frequent trips to hospital. Eventually he needed personal care and he had to receive palliative care at the end also. He was really thin when he died. If you look at the photos of him, you can see that he had really aged. He went from being young and fit to looking quite elderly when he died, yet he was only 46.

3. When my Brother and I were studying for our GCSE's and A-levels he would come outside in the sun and sunbathe but that would never have happened five years before that. There is absolutely no way he would have laid on a sun bed. He was always out and about or down the beach sailing. 18 months before he died, he spent a lot more time resting, and his activity levels weren't even close to what they had been previously.
4. I can't remember the treatment he was first on for HIV, but I think a few years after his diagnosis he was given AZT. I had forgotten, but my Brother recently reminded me of the alarms he used to have which reminded him to take the drugs; there were just so many of them that I can't remember what they all were. The AZT may have delayed certain aspects, but the HIV already had a good hold on him by then. I don't think my Dad ever faced any difficulties in accessing treatment. He was well provided for and no one refused to treat him because of his positive status.
5. I think some of the drugs he took had quite severe side effects. Some of those side effects caused damage to his nerve endings. That impacted on his ability to write. The whole family were quite big letter writers. I was away at college and that meant eventually he couldn't write to me. I remember one of the last letters he did write, one of my friends had asked me who wrote it because it looked like 4-year olds writing. He just couldn't hold a pen anymore. I think the nerve damage in his toes and feet led to him not being able to walk. He then had the added impact of not being able to hold onto and grip things and that affected what he ate and drank. He then had to have special implements in order to feed himself. He found that quite frustrating. When he was bedridden his concentration was affected because of the drugs he was taking. He was always an avid reader so when he couldn't do that anymore he found it difficult. He couldn't stimulate his brain because it was addled with all the medication that was taking. He may have been on anti-depressants, I'm not sure.
6. In addition to being a haemophiliac my Father was a through hip amputee. He had his leg amputated as a consequence of haemophilia when he was

about 20 or 21. He used to wear a false leg. An aluminium one for everyday wear and a special wooden one he had created himself to wear down to the beach so that he could still swim and sail which he enjoyed immensely. I can't remember when he stopped wearing his leg. There are pictures when one of the French exchanges came to visit and they were out on a day trip and he was on crutches. It was probably three years before he died so it had had a huge impact on him even by then. The impact on my Dad's life was massive; it just led to everything stopping. It all happened over a period of 6 years but within 3 years he had stopped wearing his leg. He had lost weight and was much weaker by then. He went from being a fit man to a man who had just deteriorated over that time. He was a very gregarious character, very sociable and would meet up with friends frequently before he became ill.

7. We always used to have parties. We a massive party in the garden for his 40<sup>th</sup> birthday where hundreds of people came; it was probably the year before he was diagnosed. We didn't have any parties after that. He used to bring people home from the pub that he met but all that stopped. We used to go sailing without him; we were quite young and had to have an adult with us, so Mum would come. I was probably about 14 or 15 if that. Previously we would always do that as a family of four. After he became ill, it was more noticeable that it was only the three of us.
8. By the end he had to rely on my Mum, Brother and I and the Nurses for palliative care. Until about 2 years before he died he would sometimes still go out but didn't have the same energy which meant he had to curtail his socialising significantly. People may come and see him, but because of the tiredness he wouldn't always be able to receive visitors or if he did it would only be for a very short period of time. Even that had to stop in the last few months of his illness.
9. It was a hard time to share your HIV status as there was quite a lot of stigma attached to it. He would have thought about the effect it would have had on my Brother and I as teenagers in the community if it had become known. We told members of the family and we were very lucky that they were sensible

people who offered a lot of support. Mum and Dad protected us a lot. I'm not quite sure when and how family members became to know about it but eventually everyone was on the same page. I remember a time when my Uncle John came up to visit. I was trying to help Dad onto his commode and my Uncle started crying. He was much more upset than I was because it was normal for me but upsetting for him to witness. We had always taken on a lot of responsibility, but I think my Brother and I had a heavier chore because of what happened. My Aunt often says we would have been considered to be young carers in this day and age.

10. I don't know what it would have been like if he wasn't ill. However, in one way as he was quite an opinionated person before he died, I think my life was made easier. I think he would have wanted me to get married here rather than where I wanted to. I'm sure he would have wanted to be in charge, but I am very much my own person and like to do things my own way. He was quite thoughtful for the future with me as I had to leave home in his last year. He was very encouraging and supportive of me as he knew he was going to die during the period I was doing my degree. He was very strong about saying not to come home and look after my Mother and that I had to look out for my future. He was very determined and keen that I should succeed, and we had lots of those sorts of chats. He insisted that I brought my college friends home to meet him as he knew he would never be able to go to college to see them. I think my Brother was sent to the Tech in GRO-C and had digs at 16 because my Dad was ill. I don't think my Dad wanted him to have to look after him and take on the responsibility that comes with having a parent that is terminally ill. My Brother took on a lot of responsibility when he was home every weekend.

11. I mixed in a crowd of girls so didn't really experience the stigma with HIV and the association with homosexuals. I was in a more female environment so never really had to put up with those comments that maybe my Brother had heard. I didn't share his status with anybody. I was under the impression that my Mum and Dad suggested it was best to keep it to myself.

12. The difference to the grades I was supposed to get at my A-levels and what I actually achieved was huge. At the time I didn't think it had an impact on my education but looking back maybe it did. Although, it could also have been due to not studying hard enough – who knows. I still went on to University and probably did the same course I would have done. It would be interesting to know what teachers in the school thought at the time, to get their point of view.
13. Mum was very good as a carer, as was my Mum's friend Marian who was a Nurse. Her children were the same age as my Brother and I and we had massive support from her. She cared for us, gave us emotional support and fed us regularly; we practically lived in her house. Dad's sister Ruth was really good too, especially with my Brother. We were well supported by the female members of the family.
14. We were basically adopted by Marian when my Dad was ill. It is difficult to quantify things but the impact on Marian was massive. For the last 2 summers before my Dad died, we were always around her house, and we were fed there too. She was working and supporting Mum, but she gave up working a night so that she could look after Dad. All this must have had an impact on her and her family, not least financially. They had five children between them but still helped us out so much. Neil, Marian's husband, would be cooking for seven teenagers while Marian was over here looking after Dad. Mum and Marian were tied up with Dad so much of the time
15. My Mum's brother John was devastated. He was 13 years younger than Mum, so he really looked up to my Dad. His own father was a bit old school so Dad was a more modern role model for him. My Dad had quite a close relationship with my Cousin Ian and it must have been really hard for him too. It was difficult for everyone when he died. It was really sad for my Mum's twin sister and her husband also. They were really close, and they had gone through their courtship together. It was very challenging for my Nana and Grandad, my maternal Grandparents. I think when Mum married Dad, they had some concerns about the haemophilia, but they didn't realise



the consequences would be quite so horrendous. It had a massive impact on my paternal Grandparents, Naini and Taid. When Dad was ill it was obviously a really challenging time for them. After he died, whenever I would visit, I always thought they were so very sad. They were sad for years and never really got over it.

16. Our Grandparents spent much more time up here due to Dad's illness as they obviously wanted to spend as much time as possible with him. They also wanted to help Mum as much as they could. They had their own caravan in the field so as not to feel like they were a burden. On the plus side it meant that I spent more time with them.

17. Taid was a vicar and there was a massive discussion between the adults on whether it should be a Humanist or Christian funeral. My Father didn't have a Christian faith, so he had to wrestle with his conscience about what he wanted for his funeral and what might be best for his parents because of their beliefs. It was a big issue for my Mum and Dad to discuss but I'm not sure if they ever talked about it with Naini and Taid. In the end Dad opted for a very low-key Christian ceremony in a crematorium just so there was a nod towards their belief.

18. There was a financial impact on our family as Mum stopped working to care for Dad and there wasn't a lot of money around then. We were at home looking after Dad, so we never went out much anyway. The fact Mum had to give up her job was very difficult for her. She did try and protect my Brother and I from a lot of it and made sure we were well looked after.

19. Dad used to teach people to sail down at the beach during those deregulated years and because he became ill he could no longer do that. He also did public speaking on the rugby scene. He started doing it locally and then did it regionally but because he was good, he got more and more engagements. Again, this had to stop after he became ill. He was an English tutor and would do gardening in cottages in and around the local area. He had his fingers in

loads of pies. He always had such grand plans. This all stopped when he became ill and could no longer work.

20. I found it quite hard after I had my first baby, knowing that my Dad would never get the opportunity to meet him. I think that affected Mum as well. She's not a very emotional person, but I remember her saying at the time, 'ooh, your Dad would have loved him'. You are a bit of a mess emotionally after you have had a baby anyway but that just completely set me off. You don't really measure it because you are not aware of the loss most of the time. My children only have one Grandparent now, so they have lost out on that potential relationship.

21. I live in the area where my Mum and Dad used to live. My Son plays rugby for my Dad's old rugby club and there is a reason why we go to there. I see people that used to know my Dad when he was younger, and they are very pleased that we still have the family tradition going on.

22. I took part in a TV programme this year and I told my Headteacher at the school I work at because I was aware that, even in this day and age, there may be some sort of comeback. I thought there was a possibility that some of the parents may complain that I was associated with someone who was HIV positive and the perceived stigma. Nobody did complain so that was very positive. It was called Y Byd Ar Bedwar, which is like a Welsh media Panorama and they also did an English language version of it on Wales This Week. It was just to raise the profile of the situation before the Public Inquiry. They needed a Welsh speaker which was why I was invited and not because I had been involved in the cause for years and years like some of the people had.

## 6. Treatment/Care Support

1. I don't think my Dad ever faced any difficulties in obtaining any care, treatment or support as a consequence of his HIV status. I was never offered any counselling or psychological support during the time my Dad was ill or

after he died. Although to be fair at the time, if I was offered, I would have probably thought that I didn't need it. In hindsight though it would have been good if it was offered to us.

## 7. Financial Assistance

1. We had to have alterations done to the house after my Dad was diagnosed so that he would be able to maintain his independence for a longer period of time. I think my Mum and Dad applied for:   however my Brother has said to me that he thinks it was a grant. I know there was definitely a point that my parents had to   because I remember the Bank Manager coming around for tea, which wasn't completely unusual in those days if you:
2. I don't know if my Dad received any money from any of the trusts. My Mum did after he died, I think she received about £60,000 but I don't know the details or what was involved in it. I'm sure my Mum will have provided that information in her witness statement.
3. I was given £8,000 about a year after Dad died from The MacFarlane Trust. I was supposed to have £7,000 and my brother Sion was supposed to have received £9,000 but Mum split it equally as she thought it was fair. I was over 18 at the time, so I think that was why it was supposed to be less for me. I was a student at the time, so it was very welcomed. I don't know how my Mum applied for money from the Trust or about the processes involved.

## 8. Other Issues

1. I was involved in a recent TV programme and as a result of that I had to go to a meeting. Outside the meeting people were protesting and campaigning for a Public Inquiry so I joined in. However, I don't want to take any credit whatsoever for that because the people that have brought the Inquiry about have been campaigning for years and years and we are all benefiting from their hard work.

2. I would like to further mention the impact of all of this on Neil and Marian. They are not family members but they are as close to family as possible. The Inquiry is focusing on those that were infected and their family members. I just think that very close friends like Neil and Marion are not getting the recognition they deserve yet it had a huge impact on them. They were very closely involved in my Dad's care, in supporting us and my Mum. Marian even laid my Dad to rest. She was a Nurse so did all of the post death preparation before he went to the undertakers. I understand the Inquiry cannot look at the impact on everyone who has been affected by a person who has received contaminated blood as there are so very many of us but I think it is important to recognise the ripple affect beyond just immediate family.

**Statement of Truth**

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

Signed... GRO-C

Dated.....18/02/19.....