

Witness Name: Beverley Tumelty
Statement No:WITN2412001
Dated:17th March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF BEVERLEY TUMELTY

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, Beverley Tumelty, will say as follows:-

1.Introduction

1. My name is Beverley Tumelty. My date of birth is GRO-C 1965 and my address is known to the Inquiry
2. My Brother is Gareth Lewis who was born with haemophilia A and infected with HIV and hepatitis C (HCV) as a result of receiving contaminated blood.

2.How Infected

1. Gareth had lots of problems growing up due to his haemophilia. When Factor XIII came out in the 1970's everyone thought it was a wonder drug that cured

all bleeds. In the early 1980's we became aware of gossip where haemophiliacs were being called back for tests as there was something being found in blood tests. As far as I can find out Gareth was told in late 1984 that he was infected with HIV but after wading through his notes the documentation is very poor with large chunks missing.

2. I was told that Gareth had HIV in late 1984. He had only recently been told that he had contracted HIV and at that time life expectancy was only months and he had been told that he would die. HIV at the time was a massive death sentence and I remember adverts on the TV at the time about HIV with a tombstone. There was so much scaremongering and it was a horrible time. I was sure that Gareth would be dead by the next Christmas.
3. The antiviral treatment at the time was AZT. People were dying at that time because of the doses of AZT they were being given and not HIV. AZT compromised the immune system and secondary infections were pneumonia and low white blood cells. Gareth was poorly on and off with all sorts of issues. He would take his medication then he wouldn't take it. He was never consistent with his medication.
4. It was horrible when Gareth told people he had HIV. His friends and work colleagues were weird with him for example bleaching mugs and not using the toilet after him. Gareth lost a lot of friends and jobs because people were scared of the HIV but this was mainly because of their lack of knowledge and education.

3. Other infections

1. Gareth had his first blood tests for hepatitis C (HCV) in the early 1990's. He was first told that he had Non-A, Non-B hepatitis but was later told that he had hepatitis C (HCV) as well as HIV. He managed to clear the hepatitis C (HCV) to an undetectable level through treatment.

4.Consent

1. Gareth was treated without knowledge and consent. I don't think that he had any choice in the matter. Factor VIII was sold to them as a miracle treatment for haemophilia. He definitely wasn't given adequate information in regards to the risk of infection.
2. He was treated for the purposes of research and by doctors of the attitude of 'lets see how this all pans out.' Looking back at some of the documents that have been uncovered PUP's was most definitely a thing. The doctors just thought they could deal with whatever the storm was. Professor Bloom at University Hospital of Wales knew Gareth from a child and was always very nice. From a nursing point of view I can see the scientist and researcher in him just wanted to see how things evolved. However, once he knew about the muck in the treatment that was being imported I can't forgive him for continuing to use the treatment.

5.Impact

1. Gareth was newly married when he was diagnosed with HIV. Gareth and his new wife, Carol, GRO-C
GRO-C Their relationship broke down, I believe, due to the way Gareth was after being diagnosed and not being able to have children.
2. When Gareth's marriage ended he went AWOL. He got a little flat and we didn't see much of him. He was angry and non compliant with his medication. It was almost like we had lost him already. He retracted from the world and had bouts of depressions. I lost count of the amount of times I thought that Gareth was going to die with the number of admissions to hospital due fo infections. He was on an inhalation drug called Pentamidine and this rotted his teeth and he lost them all.

3. After his first marriage broke down Gareth did meet someone else; Tracey. Tracey already had 2 children of her own and was very supportive of Gareth. They married and were settled and happy for a while and he integrated back into the family again. Tracey was great but their relationship did break down. There are 2 sides to every story and at times I felt that we couldn't get the whole truth out of Gareth so we never quite knew whose story was right or if we were getting the whole story. Living with HIV and constant illness and upset ruined his relationships.

4. The breakdown of his marriage led to a very difficult time for Gareth. He went off his medication again and was very ill. He was still campaigning and trying to gather evidence but was overwhelmed with sadness. Gareth had a drive and determination not to die and that stemmed from the death of little Colin Smith, a 7 year old boy who died after contracting HIV from contaminated blood, and the birth of my son Joe. [GRO-C]
[GRO-C] and Gareth was a massive support to me and Joe. Joe really looked up to him as both an Uncle and someone who [GRO-C]

5. I miss Gareth everyday. I have grandchildren now and my 1st granddaughter was born on Gareth's birthday. We talk about Gareth all the time as a family and all the grandchildren know who Gareth was.

6. Treatment/Care Support

1. Gareth went through a really bad period in the 1990's. He was ill again with pneumonia and the hospital put him on steroids. He basically took a lot of steroids in a short period of time and stopped taking them suddenly. It was a horrendous time because stopping taking steroids that suddenly initiated a manic episode. He should have been sectioned at the time. As a family we had to be on watch over and supervise Gareth 24 hours a day for around a week. The best way I can describe it is that he was like a 5 year old for that week.

2. Gareth became well again and resumed his campaigning and working with the Birchgrove Group/Tainted Blood. He moved to Birmingham in the late 1990's and met Jackie and they were engaged but never married. That relationship also ended but he continued to live in Birmingham. We still saw Gareth quite a lot whilst he lived in Birmingham as he was often back and forth to Cardiff. He would come to see Joe and take him to Cardiff City matches and always came down for family parties and get togethers. At one point Gareth needed a hip replacement so he came to live with us for 6 weeks. It was a fun time and lovely to have him in the house for an extended amount of time.
3. Gareth definitely experienced difficulties in obtaining treatment for both the HIV and hepatitis C (HCV). Some of the health professionals he saw were scared and didn't want to treat or look after him. Many were insensitive putting high risk stickers on blood bottles in full view of other patients. I witnessed a Phlebotomist shout over a unit that Gareth was high risk and to double glove. The Phlebotomist then shouted Gareth's name over the ward so all of the other patients heard.
4. In December 2010 myself and my husband Ian had arranged to go to see my brother Mark in Spain and were going around 2 weeks before Christmas. Gareth was due to go over on around the 22nd December but he decided to go early and come over with us. We got there on the Friday night and had a great time. The Saturday night we all went out into the village and were drinking, singing and dancing. My daughter had also come out with us with her friend. I left them to it at 3am and everyone else including Gareth were still up drinking until around 6am. The Sunday ended up being a quiet family day.
5. On the Monday we had arranged to go out for the day and as there were so many of us we had to go in 2 cars. I remember Gareth being excited and well. Gareth travelled in a separate car to me and as we pulled up my sister in laws dad was frantically waving at me to get my attention. As soon as I looked at his face I knew that something was wrong. Gareth had collapsed

halfway out of the car but was still conscious. I knew he was having or had had a stroke as one side of his body was not functioning.

6. My nursing instinct then set in and I got him on to his side to open his airways. There was an emergency clinic nearby and we raced to get him there. The clinic were fantastic. We told them immediately that Gareth had HIV and that did not affect his care. They said that Gareth had had a cerebral event. They told us that they needed to transfer him to the local hospital for a head CT scan. At the local hospital we were told that he was gravely ill and had had a massive bleed both an intercerebral and a subjural haemorrhage. We were told that the local hospital needed to transfer him to the hospital in Malaga who had a neurosurgical department.
7. I am a Neurological Nurse but the hospital wouldn't let me travel in the ambulance with Gareth and he had to travel alone with us following behind. We didn't see Gareth when we got to the main hospital in Malaga and as we arrived we were asked to go into a little room. I knew what this meant. We were told that Gareth had a devastating brain injury and was not compatible with life. They were unable to operate or ventilate and were going to transfer him back to the smaller hospital and make him comfortable.
8. Gareth collapsed at around 11am and passed away at 8pm.
9. Gareth did receive counselling and support. He went to Relate, saw social workers and had informal counselling from Tainted Blood and Birchgrove Group. I have personally had counselling through the Terrence Higgins Trust Wales and Tenovus. It sort of helped and it is sort of cathartic to talk about it but I still don't think any of it makes sense and both Gareth and Haydn, my other brother, should be alive. It's just wrong from start to finish.

7. Financial Assistance

1. Gareth had assistance from The Skipton Fund, the Macfarlane Trust and various grants and awards. He had an ex gratia payment of around £20,000

when he was first infected but was pressurised into signing a waiver agreeing to make no further claim for compensation or payments.

2. Gareth didn't work from the 1990's apart from in a voluntary capacity. He was on benefits and grants and constantly had to apply and prove his worth. It was horrendous and degrading constantly having to repeat the same story any time he made a new application.

8. Other Issues

1. From anger Gareth started a support group at the Birchgrove pub in Cardiff which was called The Birchgrove Group. It was originally set up, with our brother Haydn, to support those infected with hepatitis C (HCV) and HIV through contaminated blood and to have somewhere to go to chat. The group evolved and got some funding to develop it. Gareth was Chair of the group and helped get support for families, arrange away days and raise awareness.
2. The Birchgrove Group evolved into the Tainted Blood Group with more focus on campaigning. They gathered documents and evidence together and campaigned for a Public Inquiry. Gareth was actively seeking the truth behind why so many people were infected with contaminated blood. He was never looking to blame one person. He attended protest marches and even went to Scotland when Bill Clinton was there.
3. At one of the Birchgrove Group away days I was speaking to a Nurse from London. She described Factor XIII as a soup and "full of shit". We always knew that England got the newer and trendier treatments first which just reiterated Gareth's view of treatment being a postcard lottery.
4. Gareth hated the Haemophilia Society and believed that they were complicit in the use of contaminated blood and hid a lot of things. He believed that monies that the Society received were not put in the direction that they were meant for.

5. Gareth was always open about his HIV and went on different TV programmes in his campaign for justice including Newsnight, This Morning and Breakfast Time. Gareth at one point had a lot of documentation from his various campaigning but after he passed away and I went to clear his flat a lot appeared to be missing as there was a lot less documentation than I thought there would have been.

6. Due to the fact of his HIV Gareth had no insurance and we were unable to repatriate his body to the UK when he died. We had him cremated in Spain and then brought his ashes back to the UK. We arranged a memorial service in Cardiff and I think the sheer volume of people that attended was a testament to the respect he had within the campaign groups and haemophilia community. It was a very difficult decision as a family not to bring his body home and the delay in arranging a memorial service increased our distress and grieving process.

sStatement of Truth

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

Signed...

GRO-C

Dated.....

17/3/19