

Witness Name: Beverley Tumelty
Statement No: WITN2412007
Dated: 17th March 2019

INFECTED BLOOD INQUIRY

SECOND 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 Haydn 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. Haydn is my eldest brother and the oldest of five. I was the only girl and the youngest sibling. Haydn was like a Dad to me as he was that much older than

me. He looked after me when we were little and he was always there. We were like a little gang the five of us with Haydn being the most constant. Haydn and I were big mates and he looked after me especially with me being the youngest and the only girl.

2. Haydn met Gaynor when they were both quite young and they married when Haydn was 19. We all just knew that they would be together forever and they had two boys Steven and Paul. Haydn and Gaynor did everything together where one was the other went and haemophilia greatly affected their lives.
3. Haydn had so many bleeds it was ridiculous. He had no Factor VIII levels so was classed as a severe haemophiliac. His knees and ankles were where he had most of his bleeds and his main problem joints. He spent massive periods of time in hospital when he was younger and was often in a leg brace or splint. In spite of this he managed to get to school and finished school. After he left school he became a Carpenter and he was so skilled at it and took a lot of pride in his work. He was genuinely just a lovely guy.
4. Haydn found out that he was infected with HIV in 1984 and it was horrible. Haydn and my other Brother Gareth's stories mirror each other very closely. There was a lot of scare mongering at the time regarding HIV and people were so badly misinformed. Haydn's biggest concern was his family. He had 2 young sons and was worried that he wouldn't be allowed to play with them, cuddle them or see them grow up.
5. The thing that broke Haydn's heart was that he infected his wife Gaynor. Haydn and Gaynor had decided that they had had their family and Gaynor was sterilised. The delay in the hospital in Cardiff (University Hospital of Wales) telling them of Haydn's HIV was the cause of Gaynor's infection. This was heart-breaking for Haydn and I don't think he ever got over that.
6. Haydn was much more stoic about the HIV than our brother Gareth. Yes he got angry and became obsessed with finding the truth but as he had Gaynor and the boys he just coped a bit better with finding out he was infected apart

from the issue with Gaynor's infection. It was a very scary time for Haydn and Gaynor.

3.Other infections

1. Haydn was infected with hepatitis C (HCV) in addition to the HIV.

4.Consent

1. In regards to consent Haydn's wife Gaynor will discuss this in her statement.

5.Impact

1. Haydn tolerated the fact that he was infected with hepatitis C and HIV brilliantly. When he had the Interferon treatment it affected him greatly. He was depressed and initially he was awful to live with but I'm sure Gaynor will be able to elaborate on this in her statement if necessary. Haydn took various combination therapies to try and get the HIV under control which he did. Haydn was a lot more compliant with the triple therapy and medications because of Gaynor and the boys. He had them as his constant in life to survive for.
2. Haydn had joint problems and eventually had a knee replacement. One of his ankles also fused so he couldn't bend the ankle properly which was horrendous for him especially when it came to his work which he loved. When Haydn was no longer able to work he was devastated. He felt that he wasn't able to support his family properly and felt like they lived off hand-outs. Having to get grants from here there and everywhere broke Haydn as he was a proud man who had always worked and provided for his family.
3. Both Haydn and Gareth went through such physical and emotional pain but stayed sane and just nice people. They were both unselfish and worked so hard for the benefit of others. None of the family thought that they would

survive for as long as they did. They were both heavily involved in campaigning and trying to find the truth and help others in the same situation.

4. It breaks my heart that Haydn and Gareth are not here. Haydn was not alive for his sons wedding and for just everyday life. Haydn had a massive impact on so many people's lives and it's just devastating. The impact on the entire family has been massive. 2010 was a horrible year all in all and as a family I don't think we have ever got over that year.

6.Treatment/Care Support

1. The hepatitis C (HCV) was damaging Haydn's liver. He had Interferon treatment that devastated him both physically and mentally as it is such a hard regime to comply with and the effects for Haydn were horrible. Even with the treatment he just couldn't clear the virus. This led to Haydn developing cirrhosis and then liver cancer.
2. Haydn was put on the liver transplant list and was waiting for a long time for a donor. I knew that I was the same blood group as Haydn so offered him a partial liver donation. At first he said no but as time went on he eventually agreed for me to look at providing a donation. I was due to go to Birmingham, to Queen Elizabeth Hospital, for pre-op assessments and had a call from Haydn to say that he was on his way to get a liver transplant despite the issue that the donor liver was infected with hepatitis C (HCV). By the time myself and my husband got to Birmingham Haydn's transplant had taken place. He made a phenomenal recovery saying that the liver was "made for him." He was only in hospital for a week to 10 days following the transplant.
3. Devastatingly the cancer came back a year later and Haydn had chemotherapy embolization as he had been told that he was not eligible for a second transplant. Chemotherapy is one of the most painful things reported and it was so upsetting and distressing to see Haydn in such pain. I had never seen him in so much pain.

4. The February before Haydn died he was jaundiced, emaciated and only had little tufts of grey hair. He was prescribed a drug called Sorafenab for his kidneys and treatment for advanced liver cancer which ironically was made by Bayer who made Factor VIII. It was a horrendous drug. He was told that he might have some reactions and he came out in redness to his skin and blisters. He was devastated that he couldn't hold his recently born first grandchild GRO-C
5. I remember saying to Haydn that enough was enough regarding the Sorafenab. It wasn't that I wanted him to die but it was clutching at straws. He did listen and stopped treatment shortly before he passed away as it wasn't doing him any good.
6. Haydn was adamant that he wanted to die at home. He was taken in Holme Towers, a hospice in Penarth, to rehydrate him in May 2010 for what was supposed to be just the day. He just seemed to decide that he was happy there and didn't want to go back home. He went there on the Monday and died on the Friday.
7. The night before Haydn died, the Thursday, I spoke to his wife Gaynor as he was exhausted and agitated and I knew that we all needed to leave the hospice. It was like Haydn knew everyone from the family was there and he didn't want the attention. Gaynor of course stayed with him and was with him when he died. He passed away on the Friday morning so it was like he was waiting for us all to leave. To a certain extent at that time I wanted him to die as he had had enough. Haydn's death wasn't the tremendous shock as Gareth's was as in a way we were more prepared for it.

7.Financial Assistance

1. In regards to financial assistance Haydn's wife Gaynor will discuss this in more detail but I know that Haydn hated having to go to the different Trusts to get what he deemed as hand-outs and to have to almost beg for money.

8. Other Issues

1. Haydn got involved with supporting and campaigning to almost an obsessional degree. This was overwhelming for them as a family. Haydn would be so sad and angry that there are so many offshoots of the haemophilia groups and not one group all working together. If there were 2 people who could get everyone in a room together and talking it would be Haydn and Gareth. They included everyone and would be horrified with all of the scrapping and infighting. Everyone should sit, reflect, take a breath and realise how far the campaigns have come and what has been achieved.
2. I have been very quiet in the haemophilia world over the last few years after Haydn and Gareth's deaths but I am slowly getting involved and doing a bit more. I would like to help finish what Haydn and Gareth started. I would like closure of what they started and to find peace.
3. If this had been an event like Hillsborough or Grenfell where there was one event and people died on the same day then there would be more public awareness and a wider public outrage. The shock and awe on the wider public hasn't happened with the contaminated blood scandal. The numbers infected in Wales alone are huge.
4. I would like to say that Professor Peter Collins at the Haemophilia Centre in Cardiff was instrumental in keeping hold of all medical records and making sure things are done properly. He had a self awareness that everything needed to be kept for any Inquiry that may happen.

sStatement of Truth

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

Signed...

GRO-C

Dated.....

17/3/19