

Witness Name: Siobhan Tumelty
Statement No: WITN2411001
Dated: 21st March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SIOBHAN 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, Siobhan Tumelty will say as follows:-

1. Introduction

1. My name is Siobhan Tumelty. My date of birth is GRO-C 1986 and my address is known to the Inquiry.
2. My statement will be related to Gareth and Haydn Lewis, my Uncles, who were infected with HIV and hepatitis C (HCV) through contaminated blood products.

2.How Infected

1. Haydn and Gareth were both infected in the 1980's following treatment for their haemophilia. Neither Gareth nor Haydn were told straight away that they were infected. My Mum, Beverley Tumelty's, statement will go into more detail as to how Gareth and Haydn were infected.

3.Other infections

1. As far as I am aware Gareth and Haydn had no other infections.

4.Consent

1. My Mum, Beverley Tumelty's, statement will discuss the issue of consent as this is not something I have much knowledge about.

5.Impact

1. I am the niece of Haydn and Gareth Lewis. Gareth was also my Godfather so we were particularly close. Haydn and Gareth were both a big part of mine and my family's lives. They both passed away in 2010; Haydn in the May and Gareth in the December. Haydn and Gareth had both fought HIV, hepatitis C (HCV) and the associated illnesses for a very long time following being diagnosed.
2. Being diagnosed with HIV and hepatitis C (HCV) affected Haydn and Gareth differently and how they dealt with their infections was also very different. Haydn was a more relaxed man in general. He took life as it happened and got on with it. Although I know it was very difficult for him especially as he infected his wife with HIV and had 2 young sons he was more of a pragmatic man. He fought hard to find out information regarding the contaminated blood and tried hard to try to erase some of the stigma associated with HIV in the 1980's especially.

3. Gareth was a different kettle of fish. The anger and bitterness he had as a result of being infected drove him. He was very angry and this did colour who he was as a person and how he was to live with. He definitely struggled more than Haydn and had a 'why me?' mentality. He was the more impetuous person and would get an idea and just go with it. He was an amazing man and I loved him dearly but he was very unpredictable and I believe that this was a lot to do with being infected. He fought similarly to Haydn for answers but from a place of anger.
4. Haydn and Gareth were very different people with different lifestyles. Haydn had the nuclear family which gave him more stability. Gareth didn't have the nuclear family, despite the fact that he had tried but found it difficult to maintain. He had 2 failed marriages and had never had children of his own.
5. I can't remember exactly how old I was when I was told that Haydn and Gareth had HIV but it was at a young age, maybe 8/9. At that time there was a fear and a massive stigma surrounding HIV. I remember that I wanted to understand from a young age what HIV was and be open about it.
6. I remember realising that people didn't discuss HIV and I thought it was so important to discuss HIV with others and took it upon myself to tell people what it was and I was happy to be very open about HIV and its effects on my family. In 6th Form, around 2003-2005, I did a project in Biology about HIV and infected blood products and talked about it in class. I wanted to break the stigma that the 1980's had brought to HIV and the way in which the media had portrayed it and try and change people's perceptions. In University my degree was in Creative Writing so I wrote stories about Gareth and HIV in blood from the USA. I read a lot about contaminated blood and the associated hepatitis C (HCV) and HIV.

7. My Brother Joe, **GRO-C** had a difficult time after Haydn and Gareth passed away. **GRO-C**

GRO-C

GRO-C They spent a lot of time together when Gareth was alive **GRO-C**
GRO-C

8. The year that Haydn and Gareth died was awful for the whole family but I genuinely think that the worst part for me was how it affected my Mum. Mum and her brothers had a difficult upbringing and this meant that Haydn was more like a Dad to my Mum than a brother and she was also very close to Gareth. Losing them both in such a short space of time was so difficult for Mum and it was a bleak time. She is a stubborn and sensitive lady and would take offence if anyone thought that she wasn't coping. **GRO-C**

GRO-C

Mum was difficult to live with and is still difficult on various anniversaries. She is very hot on anniversaries and knows all the dates. She gets upset if one of us forgets a date or anniversary.

9. There has been a massive knock on effect on Mum and she has had poor health during the last 3 years and so has her other brother Neil. My other uncle Mark, who lives in Spain, doesn't seem to be as affected as my Mum and uncle Neil but then he didn't see Haydn and Gareth first hand as regularly. Mum and Neil say they are both cursed health wise. Mum won't admit the effects both mentally and physically losing both of her brothers has had on her. It has had a much bigger effect on her than she will ever let on. She has taken it upon herself to carry on the fight that Haydn and Gareth left behind. They campaigned for so many years for answers and justice and I think that Mum feels that she has to carry on the fight.

10. It's been almost 10 years since Haydn and Gareth died and that time has become a bit of a blur. You almost remove yourself from the events and block them out. I don't have an encyclopaedic knowledge about what happened but I can say that, as a family, it was such an awful time and it is difficult to portray in words how difficult a time it was and how it has impacted and affected the whole family.

6. Treatment/Care Support

1. The physical changes were unbelievable for both Haydn and Gareth and as their niece I wasn't right there on a daily basis but did see some of the physical effects on them. As a family we lost count of the number of times Gareth was at death's door and we thought he was going to die. I remember Mum having a book in the house about how to deal with death and the practicalities.
2. Haydn was always the one who would want to try all of the new drugs and medications as he would do anything to be around his family. Towards the end of his life he was a shadow of the man he was but he was continuing to try all of the new treatments as he was trying to stay alive for his family and his newly born young grandchild, **GRO-C**. He put himself through a lot of pain, suffering and experimentation trying to survive for his family. During Haydn's last week he was at Holme Towers, a Hospice in Penarth, and we were just waiting for him to die. It was so bleak and I can't explain what it was like because unless you have been around someone that ill you just can't imagine it. It was just an awful and tragic thing to watch.
3. It was more of a shock when Gareth died as it was much more sudden than Haydn. It sounds a strange thing to say that it was sudden for someone living with HIV to die but he had been well. There were so many occasions we had prepared ourselves for Gareth to die and he would pull through so him dying was just such a shock.

7.Financial Assistance

1. I'm unable to answer any questions on financial assistance but I'm sure my Mum and Aunt will have answered these questions in their respective statements.

8.Other Issues

1. Haydn and Gareth fought so hard for an Inquiry and it is so sad that they are not here to see it take place. They would have loved to have seen what is happening now and all their hard work and campaigning really starting to make a difference.

Statement of Truth

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

Signed...

GRO-C

Dated... 8/4/19