Witness Name: Jan Wallace
Statement No:WITN2688001
Dated: 28th March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JAN WALLACE

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, Jan Wallace, will say as follows:-

1.Introduction

1. My name is Jan Wallace. My date of birth is GRO-C 1956 and my address is known to the Inquiry.

2. I was Secretary of Haemophilia Wales from August 1999 until April 2003.

2.How Infected

1. My Son, Mike, was born in 1981 and diagnosed with haemophilia B (Christmas Disease) in 1983. Thankfully Mike was not infected with

HIV/hepatitis C (HCV). Mike had his first check up with Professor Bloom at Heath Hospital in Cardiff (University Hospital of Wales) in October 1983 and went back to the Haemophilia Centre every 6 months for check-ups. Mike has Christmas disease and requires Factor IX. My understanding was at that time there were less people with haemophilia B than haemophilia A and so the UK was more self-sufficient in the Factor IX treatment.

2. Haemophilia is hereditary in my family and my 2 cousins were haemophiliacs. As far as I am aware the severity of their haemophilia was similar to Mike's. Unfortunately, it wasn't talked about between my Mum and her sister's, so I don't have much information and we didn't see my cousins as we grew older.

3. Both of my cousins have passed away. One cousin, Ian, was infected with hepatitis C (HCV) from receiving contaminated blood products. As we didn't see him regularly I don't really know a lot about him being infected but I do remember seeing him once at a hepatitis C campaign meeting at the Village Hotel in Cardiff. I vividly remember him saying that for years doctors had told him not to worry about his hepatitis C, but he was now being told it was more serious than they first thought and people were becoming ill and some dying from liver cancer. Ian was also diabetic. When Ian died I do not remember anyone in the family mentioning hepatitis C except for Dr Dasani, at Ian's funeral, advising Ian's sister that she should make enquiries about submitting a claim for compensation for hepatitis C infection.

3.Other infections

1. I have nothing to add here.

4.Consent

1. Mike had his first HIV test on 11th July 1985 and was tested every 6 months after this until his last known test in 1994. I can understand them carrying on with the HIV tests until 1994 as there would sometimes be false negatives in tests for example.

2. At no point do I ever remember any of the doctors talking about hepatitis C (HCV). I am surprised that he was never tested. It is possible that he was tested and we were just told that the nurse was taking bloods for levels. The first time I remember hepatitis C (HCV) being mentioned is when I started to campaign for Recombinant Treatment in 1997.

5.Impact

1. As I have mentioned my Son, Mike, is not an infected haemophiliac but haemophilia does take its toll especially with mobility and pain. It also has an impact on family life and I took an active part when involved with campaigning for better services for all haemophiliacs.

2. I was heavily involved in the 1990's especially with Haemophilia Wales, but that involvement is to a much lesser degree now. It was very hard to walk away especially having got to know the people involved. Campaigning can take over your life and I have seen this happen to people I was very fond of and admired greatly. One thing I have taken away from my involvement tgen, is the knowledge that even a small group of people can make a difference. Without the tireless campaigning of the infected/affected I don't think there would ever have been a Public Inquiry. I also believe that because of successive Government's refusal to hold a Public Inquiry, haemophiliacs were held back from ever moving on with their lives and trying to repair some of the damage that had been done to them.

6.Treatment/Care Support

1. I didn't realise at the time, but having recently looked back at the notes I made regarding Mike going to the Centre for treatment, I'm positive that staff were avoiding giving Mike treatment for a period of time. In August 1983 Mike had his first Factor IX treatment. By 1984, looking back, they were avoiding giving Mike treatment. From May 1984 there were 4 occasions where Mike could have had treatment with Factor IX but was not offered treatment.

2. In April 1985 Mike bumped his left thigh which led to swelling of the thigh. I have no doubt that this was an internal bleed, as his thigh later became one of his target areas. Then he was given no Factor IX treatment by the Haemophilia Centre in Cardiff. In August 1985 they did start treating Mike with Factor IX again and from this date he was treated with Factor IX every time he was taken to the hospital except on one occasion. Around this time, we were unaware of the HIV infections; but were told that the Factor IX Mike was having was heat treated and understood it was safe to use.

3. In hindsight I'm sure that the Haemophilia Centre in Cardiff were avoiding treating Mike with Factor IX, but at the time we were just happy that he wasn't having to have treatment every time we attended.

4. My GRO-C was tested to see if she was a carrier of the gene at 11/12 years old. I was working at the hospital (University Hospital of Wales) at the time and bumped into Dr Dasani in the corridor during my working hours. My recollection is that he told me that GRO-C was a carrier. My husband and I decided that we would tell GRO-C this straight away and not keep the information from her.

5. In 2005 I was involved in some research into 'Communication within Haemophilia Families'. Doing some homework for the project I realised I had not taken a note of the date I was informed GRO-C was a carrier. I rang the Haemophilia Centre in Cardiff and spoke to Sister Chris Loran and was told that they couldn't be 100% sure that she was a carrier. She said that GRO-C would need to be retested as they had improved genetic testing and that it would be more accurate than previous tests. I broke this news to GRO-C that she would need to be retested, she must have been about 21 at the time, and she was understandably upset and refused to be retested. She continued to believe that she was a carrier and felt no reason to be retested although always hoped that she wasn't affected. She has recently been retested and currently waiting for the result.

7.Financial Assistance

1. I have nothing to add here.

8.Other Issues

1. The first time I came across a haemophiliac affected with HIV was at a meeting arranged by Sister Jenny Jones at the Haemophilia Centre in Cardiff. The meeting was for parents of newly diagnosed children with haemophilia and this was sometime during the 1980's. This was the first time that I met Gareth Lewis. He came along to talk to us about haemophilia and explained the impact of being diagnosed with HIV. Gareth had GRO-C GRO-C I think the purpose of the meeting was to help us to try not to be too over protective of our children. Gareth was brave and funny and helped us all to believe that things were going to be OK.

2. In the 1980's there was definitely a huge stigma for those men who had been infected by HIV. Those who had HIV felt that other haemophiliacs didn't want to be involved with them. When it became clear that hepatitis C (HCV) was more serious than haemophiliacs were led to believe, campaigning became more prominent and more people got on-board with it. The Haemophilia Society's Hepatitis C campaign did not include the co-infected (those with HIV/HCV). This caused resentment and a rift between haemophiliacs. Support groups became fractured. I think if the groups had worked together, they might have been more effective.

3. In my opinion the Government used the rifts and fractured groups to delay decisions. I think that they expected those with HIV to die before an Inquiry into how and why this happened took place. I believe the biggest reason there has never been a proper Inquiry is purely one of cost.

4. In 1997 I was heavily involved in the campaign to ensure all haemophiliacs in Wales received the safest treatment known as Recombinant. This was the

treatment of choice of the Centre Director in Cardiff, Dr Peter Collins (now Professor Collins). However, the Health Authorities were dragging their feet in providing funding for the safer treatment. This became even more relevant as far fewer, if any, haemophiliacs would have been put at risk of nvCJD. A group of us (many of whom became members of the Haemophilia Wales committee) wrote letters, gained support from M.P's and A.M's (in particular Julie Morgan and Dr Dai Lloyd), attended meetings with the Director of Public Health and the Welsh Office. We met with the Press, raised petitions and generally nagged anyone who would listen. On 29th April 1997 I received a letter from Mr Malo Harvey, NHS Executive, Department of Health stating 'it is for clinicians to decide whether to use plasma-based Factor or Recombinant'. This was disappointing as it was clearly not the case. The delay in changing to Recombinant treatment was purely one of funding which one might find surprising – given our history!

5. In 1999 the South Wales Haemophilia Group was reformed by Gareth Lewis and I became involved in this Group. In 1999 we were campaigning for the relocation of the Haemophilia Centre in Cardiff. A cross section of those affected by haemophilia were part of the committee including a father of a haemophiliac, mothers of haemophiliacs and 6 haemophiliacs of which only 2 are alive today.

6. On 17th November 2000 the new Haemophilia Centre opened in Cardiff. We had to fight to get this new centre as originally, as part of cost cutting measures, we were amalgamated with the Haematology Day Unit. We had to really emphasis that haemophilia and haematology were two completely different areas/conditions. One a lifelong condition involving children and adults and one acute for adults only and therefore inappropriate. Once again we wrote letters, attended meetings, raised funds for a new centre, dealt with the Press and involved M.P's and A.M's. In a letter dated 18th March 1999 the Chief Executive of Cardiff & Vale NHS Trust, Allister Stewart, stated 'the new Haemophilia Centre will provide a better environment for patient care than was previously the case'. He was talking about the space they wanted us to use in the Haematology Day Unit. Again, clearly this was not the case. As

you can see there is a pattern here. Governments and those in power have continued to put financial interests over the lives of haemophiliacs.

7. At the end of November 2000 Haemophilia Wales held an AGM and voted to separate from the Haemophilia Society and run as an independent group, as it was felt that we could better represent members within Wales. This has proved successful and still continues today (2019) under the excellent management of Lynne Kelly.

8. In 2002 I attended a conference in Seville as part of my role as Secretary for Haemophilia Wales. At the conference Dr Bolton Maggs dropped a bombshell when she revealed that the Directors of Public Health for the North West had decided not to recommend the use of Recombinant because they did not believe its use to be justified on public health grounds.

9. It's a sad, sad thing that so many of those infected haven't seen their campaigning efforts for an Inquiry come to fruition. That they won't be sat there to listen to how and why this happened is beyond words really. My hope is that this Inquiry will finally give the decision makers the chance to do the right thing.

Statement of Truth

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

Signed. GRO-C ....

Dated...28th March 2019.