

Witness Name: G Longworth

Statement No: WITN3019001

Exhibits: 0

Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GEORGINA LONGWORTH

I, Georgina Longworth will say as follows:-

Section 1. Introduction

1. My name is Georgina Longworth and I was born on GRO-C 1964. I live at GRO-C I live with my partner of 25 years and we have two children, Nathan, aged 20 and Emily, aged 17.
2. I make this statement as the affected sister of my late brother, Ronald Longworth, who was born on GRO-C 1949 and passed away on 18th March 1994 as a result of receiving contaminated Factor VIII concentrate.
3. **This witness statement has been prepared without the benefit of access to my brother's medical records.**

Section 2. How Affected

4. My beloved brother had Haemophilia A and initially received cryoprecipitate followed by Factor VIII for the rest of his life.

5. Very unusually in our family, our mother's late sister, GRO-B also inherited Haemophilia A and was one of only a rare number of females in the world to be born with this condition.
6. He was treated at the Manchester Royal Infirmary Haemophilia Centre (*"the hospital"*).
7. My brother was infected with HIV and Hepatitis C as a result of receiving contaminated Factor VIII concentrate.
8. I believe that my brother was infected with HIV and Hepatitis C in or around the 1980s, possibly around 1986.
9. I am unsure as to when Ron was told of his infection or any of the detail or advice which he may have been given in this respect.

Section 3. Other Infections

10. I do not know whether Ron was put at risk of vCJD or any other infections.

Section 4. Consent

11. I believe that my brother was tested for various viruses, to include Hepatitis C and HIV, without his knowledge and therefore without his consent.
12. With regard to research, I refer to paragraph 21 in Section 5 below.

Section 5. Impact

13. My brother died leaving his young son, Sean, who was aged 8 at the time and his partner, Kathleen Power who was Sean's mother.
14. Tragically Kathleen also died from HIV, which she caught from Ron, two years after my brother's death.

15. This tragedy has meant that Sean is now an orphan.
16. My mother, Sean's grandmother, was left to care for him and was offered absolutely no financial, practical or emotional support. This presented another tragedy in itself. We, as a family, were completely abandoned.
17. I cannot forget what happened but as a family we tried not to dwell on what happened because we had to look forward for Sean and to consider his needs.
18. When my brother was born and throughout his childhood he suffered greatly from his Haemophilia, nearly losing his life on a few occasions. My brother required treatment on a regular basis because his Haemophilia was severe; which meant it was serious, painful, debilitating and dangerous. My parents, Ronald and Joyce spent a lot of time with Ron at the hospital, where he was often an inpatient.
19. I remember going with my parents and brother to the hospital when I was a child and I would often push my brother in his wheelchair along the corridor to the Haematology Department for him to receive his treatment; which was a regular occurrence for us as a family.
20. As one can imagine therefore, the families of Haemophiliacs were very well known within this department. It would also follow and be usual for the department to offer tests to the female members of the family, as it was they who can carry the haemophilic gene. My sister, Carol, and I had these tests during our young adult lives. The senior doctor in charge of the Haemophilia Centre was Dr Hey whom I met on several occasions whilst I was young and as an adult.
21. When I became pregnant with my first male gender child in 1997, my partner and I went along to the hospital and met again with Dr Hey where we discussed the options for foetal testing because of the possibility of our child having Haemophilia. Dr Hey advised us that although it was very unlikely that our child would be born with haemophilia, he would authorise full genetic testing which he said was like looking for *"a needle in a haystack and that he had Ronnie's*

DNA in the lab". Although we were very grateful for his help, I could not believe his insensitivity and I burst into tears. I said *'what, you have my brother's DNA in the lab'*? He said 'yes'. I was very confused by this and could not understand it because my brother had died in 1994 and here was his consultant telling me he still had my precious brother's DNA; without our knowledge of course. I have no idea whether my brother would have given permission for his DNA to be retained, perhaps for the purposes of research. However, I am shocked that they retained this after his death.

22. During Ron's lifetime, there was a lot of stigma attached to HIV and Ron was very concerned for his safety and also the safety of his son and immediate family and therefore did not wish to reveal that he had, in fact, contracted HIV following treatment for his Haemophilia. He kept his HIV secret from everyone except three people, those being:

- a. His partner Kathleen, who tragically was also infected and lost her life due to HIV;
- b. Our cousin, GRO-B, to whom he was close and they shared the further devastating knowledge that her Haemophiliac son, GRO-B had also contracted HIV, but who was of course much younger,
- c. Our mother Joyce, who was loyal to her son and did not reveal it to anyone else including to my sister or me. This of course had a devastating effect on our mother as she had no one to talk to or turn to (our father passed away in 1981) and carried this burden on her shoulders entirely, whilst looking after her son and helping him in any way she could, knowing that his condition was terminal.

23. There became a point at which both my sister and I noticed that our brother had become unusually withdrawn, had lost weight and seemed a little distant. We questioned this between ourselves and concluded that he could not possibly have contracted HIV because we were sure that if this had been the case then he would have told us (we were aware that some Haemophiliacs had contracted

Hepatitis C and HIV and our young cousin [GRO-B] had already died). We were close to our brother, especially my older sister, as they were similar in age and had many happy memories and fond experiences together growing up and in adult life; having shared many times together both in business and socially. Ron had spent some time in hospital during recent years and we had visited; but of course this was not unusual.

24. We had also noticed that Ron was spending more time at our mother's house.

One day I arrived at her house to visit and observed that Ron was not very well, but that this time something was different. He was very weak and just not himself. He had lost more weight. My mother was silent, lost for words and I immediately knew what was wrong. I said *'oh my god why didn't you tell us?'* Ron was admitted to hospital within a couple of days and never came home. We visited him for 3 weeks on an isolation ward at the hospital. It was Sean's [GRO-C] and he came to visit his father, but he was not allowed onto the ward. Ron was insistent that he see his son [GRO-C] for the last time. He struggled into the wheel chair, put on a brave face and the nurse wheeled him into a waiting room where they had allowed Sean to wait. Ron passed away 4 days later on 18th March 1994.

25. The 3 weeks we spent with him on his death bed was the worst experience of my life and definitely the most humbling. Day by day, he got worse and worse. Our mother was numb; she was unable to speak any coherent language. She was sat in a chair for the whole time just unable to comprehend what was happening before our very eyes. My sister and I felt so desperate for her; she was his mother and her world was simply shattered. She was obviously exhausted and at the final hour we could see that she wanted him to be out of his pain.

26. Carol and I did all we could, but we felt empty and helpless. We both have vivid memories of this time like it was only yesterday. In Ron's final moments he could not drink or lift his head; Carol squeezed water into his mouth from a sponge. I ran out of the room screaming for someone to help him but none of the staff came. I held his hand in his final moments, trying desperately to hold

back my tears. His last words to me were *'Don't worry you can't catch it like this. Look after Sean'* and he closed his eyes for the last time at 5.55am.

27. We all just sat with him silently; he was now free of all his pain, stress and worry.

A nurse came into the room and asked us to go along to the coroner's office to register Ron's death which was in another part of the hospital. We arrived and met a doctor. Carol and I told him that we couldn't believe that our brother had died. We wanted answers; we were upset and angry. The doctor gave us his condolences. We had not met him before.

28. During our time at the hospital over those 3 weeks, we did not see any doctors whatsoever, not even Dr Hey. At no point did anyone; Dr Hey or any of his team speak to our mother or indeed to any of us. There was no programme of palliative care in place. The doctor did say he was sorry and was very sympathetic. He said and I quote *"we have administered the treatment that has killed Ronnie; there is nothing more I can say"*. We didn't know what to say to this but knew it to be true. We asked where Ron was now to which he replied, *"he's still on the ward"*. He asked our mother what she wanted on the death certificate as the cause of death and said, *"it's up to you Mrs Longworth, I am prepared to put whatever you want"*. My mother replied *"anything but that, Ronald wouldn't want that"*. My mother could not even say the word *"HIV"*. We then headed back to the ward because we just couldn't leave him; we all sat by his bed for a while and took comfort that he looked asleep and pain free. We said goodnight. My sister was unable to drive us home so a member of the family came to fetch us.

29. Ron's partner, Kathleen, passed away around two years later at North Manchester General Hospital Isolation unit. Carol and I visited her along with her three sisters a few days before she passed away. It had been decided and was the wishes of both Ron and Kathleen that our mum and grandmother to Sean would become his legal guardian; Kathleen mentioned this to us on that visit. She told us that a lady called Meg (who we believed was a consultant) but may have been a counsellor/advisor at the hospital (Manchester Royal Infirmary) would turn up at my mother's house to deal with the legalities

concerning Sean's guardianship and wellbeing. Meg had also been involved with Ron and Kathleen's care and the like. Carol and I thought this odd at the time and wondered why there appeared to be no social worker involved. In fact Meg continued to visit Sean for a few years after Kathleen passed away.

30. The very distressing death of our brother has had a profound effect on both my sister and I; we have never been able to move on because so many questions remain unanswered and coupled with the shocking information that emerged later, that the Department of Health knew about the contamination within its blood products but ignored it, has made it near on impossible. Our brother was a victim of their disgraceful policy and paid for this with his life.
31. As a Haemophiliac he battled with internal bleeds several times which nearly killed him. It must have been horrific for him and the other Haemophiliacs knowing that they were going to die as a direct result of the very treatment that was supposed to save them. My sister and I feel robbed and deeply upset that we never had chance to spend as much time as possible with him. Had we had known about his fate, things would have been very different in that we could have prepared and helped our mother to care for him and to have helped her too. The shock of finding out in that way has been very hard to cope with. Both my sister and I understand why it happened that way, nonetheless we feel that the obvious pressure the victims were under both from the public and the Department of Health meant that they perhaps felt unable to talk about it out of pure fear. Not a day goes by when I don't think about Ron and the final moments with him in that hospital room; I am still very tearful to this day and even now writing this statement.
32. The effect it has had on our mother has also been devastating and she was clearly unable to cope with the guilt she felt and the loss of her son. Consequently, she began to drink heavily and over time this has affected her health. She has never been able to talk about this with any great depth with either my sister or I. It is clearly a deep rooted heartache for her. She surrounded herself with photographs of Ron whilst taking comfort from looking after her grandson. Of course, this was not easy being a pensioner either, both in terms of age and financially. She was also a widow who only received a very

small payment which was about £22 per month to look after all of Sean's needs. I am not sure where this money came from but it was a derisory and insulting sum.

33. Clearly the stigma associated with HIV at the time meant that both our brother and mother could not reveal or speak about it for fear of reprisals. This is deeply saddening and such a burden for my mother to have carried for all of those years. Furthermore, we have since learnt that victims were told that they should not speak about the infection at all and had to sign a non-disclosure agreement, the waiver, before any compensation payments were made. We are not aware if Ron signed such an agreement.

34. The lack of humanity for my mother and our family was truly disgusting. Notwithstanding this of course, is the total failing of the Government to ensure safe practises resulting in the loss of so many innocent lives. The course of action they took was to look the other way, say nothing and hope for the best, bullying their patients/ victims and their families in the process. They also adopted a policy whereby local hospital consultants "*took charge*" of the victims, dealt with any compensation payments, hushed them up and then ran a mile as soon as possible. Such behaviour was totally outrageous and shameful. We have had no explanations, no apologies; all we have is a cover up. All of this could have been avoided.

35. Furthermore, to add to our heartache is the knowledge that today, science and medicine has remarkably found a cure for Haemophilia and our loved one may well have been able to live a longer, pain free life, free of his blood condition. How wonderful this would have been for him and his son Sean. We find it very hard to accept what happened to him and therefore have been unable to move on; we need answers and the people responsible must be held to account. Justice needs to prevail; this was no accident.

36. Finally turning to Sean; he suffered with mental health issues which became apparent to us during his early adult life. Growing up, he seemed happy and appeared to cope with the horrific situation in which he found himself in having lost both his parents to HIV and in such circumstances at a very young age. We

sought help for him, as we could see he was in a very dire state and his GP referred him to the Stockport Mental Health Team, where he received care for several years. It became very clear to us that Sean's condition was very complicated and it seemed a slow process of help, but nonetheless it was help as we saw it. Sean was insistent he was not getting the right help and felt there was no point in carrying on with the programme and removed himself from it. We tried all we could to ensure that Sean continued, as we knew his condition was severe, but he refused and blamed us for interfering.

37. Unfortunately, there have been incidents with Sean towards his family that have been both troubling and dangerous and this very sadly has meant that Carol and I have no relationship with him anymore and this upsets us tremendously.
38. We are both very concerned for his welfare. He does not visit his grandmother despite her old age. Obviously, this has caused us all great distress and worry. We have told the authorities how concerned we are and have repeatedly asked them to help, but they say that if Sean will not accept the help, then there is nothing they can do. We firmly believe that Sean is suffering the traumatic effects of losing his parents at such a young age and in the most distressing way.
39. It is also our understanding that Sean was told that there are no records of his mother having HIV and that she died of another condition that she had. However, although we are aware of another illness, this was aggravated and made worse by the HIV. This is another cover up and is both sad and infuriating.
40. Sean suffers from stress and social anxiety and therefore has an inability to communicate fully with people and cannot cope with situations that are stressful or complex. He is unable to work because of his condition and therefore struggles financially. At one point I reached out to the Haemophilia Society and asked if they could help due to his circumstances, but they said, 'no sorry' and gave me a telephone number for the Tainted Blood Charity, but they could not offer any real help. Nobody has offered Sean any psychological help during his childhood or since and it appears that no one cares. In fact it is clearly evident that no one cares. There was no provision for any help whatsoever for poor

Sean. He was robbed of his parents unnecessarily and has paid the price. The Government also failed him.

41. In conclusion, Ron was a wonderful person who despite his Haemophilia, did not let anything get in the way of his life and tried to make the most of it, despite constant internal bleeds which were always very severe and would usually ground him for long periods. He needed lots of help from the people around him during these periods. He graduated with a distinction from Nottingham College as a Horologist or as he would joke, a '*master of time*'. He loved his work, his life and his family. He was the bravest, most intelligent, hardworking, generous, caring, loving son, father and brother. We miss him every single day.

Section 6. Treatment/care/support

42. I am unsure as to whether my brother suffered any barriers or obstacles in relation to receiving medical care. However, I refer to paragraph 24 in section 5 above in relation to him being on an isolation ward in the hospital.

43. Other than a few visits from Meg to my mother's house, nobody from the Haematology Department or from anywhere else visited my mother or has been in touch with her to this day.

44. My brother, mother, sister and I have never been offered any counselling or psychiatric support. I am disgusted with this; we were simply forgotten, provided with no compassion and left to deal with our loss without any explanations whatsoever. Of course, the authorities purposely slid into the background, hoping for no reprisals or blame. The hospitals had their instructions no doubt and we are all very bitter to this day.

Section 7. Financial Assistance

45. I believe that my brother received a payment from one of the trusts as compensation, but we are not entirely sure of this.

Section 8. Other Issues

46. This tragedy has been hushed up and swept under the carpet. The matter has been completely whitewashed in the past and people have not been able to speak out.

47. I want to know why this tragedy was allowed to happen, exactly what happened, why it happened and what is going to be done about it.

48. I think that the infected and affected need some sort of closure from this Public Inquiry.

Anonymity

49. I do not want to be anonymous and I do not wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.....

GRO-C

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Dated 17 April 2019