

Witness Name: Helen Northwood

Statement No: WITN1046001

Exhibit: WIT1046002 - WIT1046010

Dated: 13 October 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF HELEN NORTHWOOD

Section 1: Introduction

1. Helen Robertson Northwood of [GRO-C] make this Statement to assist the Infected Blood Inquiry in relation to its investigation arising out of the tragic circumstances of the death of my late husband, Gary Northwood.
2. I am a widow of a person with Haemophilia who received contaminated Factor VIII concentrates for his Haemophilia A condition.

Section 2: How Affected

3. I am the wife of the late Gary Northwood who was born on the [GRO-C] 1945 and tragically succumbed to the effects of both HIV and Hepatitis C infections on the [GRO-C] 2010.
4. I have two children, Matthew and Sarah who were very young at the date of diagnosis of Gary with HIV. Sarah was only aged 2 ½ years and Matthew was aged 5 months. The time of diagnosis of Gary's HIV infection was the [GRO-C] 1985. It was a very different era and time period and we did not realise as a couple as to what this viral infection would mean in the context of life and quality of life.
5. Gary was a person with severe Haemophilia A with a Factor VIII level of less than 1%. Accordingly, he required treatment for his Haemophilia condition in relation to

spontaneous bleeds, traumas and was regularly in receipt of Factor VIII concentrates. At all times, Gary relied upon his Medical Advisors in relation to the selection of Factor concentrates. In addition, Gary was careful in terms of ensuring his quality of health by taking treatment to minimise the effects of bleeds particularly into target joints.

Exhibit WITN1046002.

6. It is noted that many of the circumstances in or around 1982/83 related to bleeds into his left elbow, right elbow, right ankle, left wrist etc. In other words, treatment was a necessary requirement to alleviate the consequences of pain arising from a bleed into a joint. At no time did Gary have any input in relation to the selection of the source of the Factor concentrate concerned. The sole extent of Gary's involvement was to determine whether the injection would be in his left or right arm. **Exhibit WITN1046003.**
7. It may be a cliché to say it but when I saw Gary it was love at first sight. I saw him across a bowling alley. He was to use a terminology very Buddy Holly-esque, a person that struck me as being somebody I wished to know.
8. After a couple of weeks, I was at a village dance, I was with two of my friends, who arrived into the hall with Gary. I arranged that my two friends would hook up with Gary's friends so that I maximised my opportunities.
9. We struck up a very strong friendship and then relationship. I recall 1968, a very different time, a time of Beatle-mania and a time that was great in terms of excitement in relation to life itself. In that year, which was a Leap Year, I recall in February 1968 sitting on Gary's knee and asking him would he marry me. I realised that he would never pluck up the courage to ask me, so I took my chance on that day.
10. Then there was the issue of getting permission from my Dad who was somewhat stern in his approach to old-fashioned values. Initially he said to us that if we still felt the same about each other after 6 months, we could return and ask the question again. We got engaged that Christmas Eve and we were married on GRO-C in GRO-C
11. That was the beginning of a great life together in that we were in each other's pockets. We went caravanning together, camping, we toured the country, we lived life as a young couple experiencing life itself.

12. One issue arose in that after 12 years it became apparent on medical advice that we couldn't have children. Gary himself had been adopted and we decided that we owed a duty to adopt. We started that process. In 1982, I discovered that I was pregnant with our daughter Sarah. She became what I would term the miracle baby and it was a really special occasion.
13. Although it was an absolute certainty that Sarah would be a carrier of Haemophilia, no precautions were taken associated with the delivery. Fortuitously, although it was a natural delivery, there was no requirement for any intervention with forceps and therefore, no risk occurred.
14. It was only at aged 6 years, that Sarah was diagnosed as being a carrier of Haemophilia A. That was the beginning of another journey in life in that her son, GRO-C who is now aged 5, is a person with severe Haemophilia A i.e. the exact same Factor level as his Granddad. During the period 1982 to 1985, we were providing all the necessary support to Sarah as a young baby and a young infant. Also at that time, I now realise that Gary was injecting himself with contaminated Factor VIII concentrate as part of the home treatment programme that resulted in his HIV infection. Obviously, we had no idea that this event was occurring, nor indeed were we appraised in any way of the risk associated with the treatment that was then prescribed. From review of his medical records, it is noted that Gary received American Factor VIII on one occasion and because of that, there was no apparent need to test him for HIV. It was only in 1986 that we were alerted to the fact that there was a safety concern with the treatment and the pharmaceutical company Amour were withdrawing their product. **Exhibit WITN1046004.**
15. Obviously, as the parents of a young child there is no way that we would have taken a risk in relation to the safety of my family and more particularly in relation to Gary's own life expectancy. We needed a situation to occur where both parents were available to be able to rear our child to maturity.
16. Lightning struck again, and I became pregnant, this time with our son, Matthew, who was born on GRO-C 1985. We were very lucky in that we now had two young children who were very much a blessing considering the difficulties that I had experienced in terms of pregnancy. Life was on the up, we were now a family and we were looking forward to all of the things that family life brings.

17. That perspective was shattered within 5 months. I noticed a lump on Gary's neck, he had tests done and we later found out he was HIV positive. I don't remember that exact date but it was around March 1985 when we found the lump. **Exhibit WITN1046005.**
18. Somewhat unusually, Gary received a telephone call from Dr. Howes at Bedford Hospital (where Gary also worked) to attend with him. He went to the appointment and it transpired that he received devastating and life altering news of his HIV diagnosis. Nobody was with Gary at the time of that diagnosis, I was at home with a young baby, Gary arrived home to tell me his awful news. He was absolutely distraught, devastated and indicated that "they have given me a slow sentence of death." I cannot convey the sentiment in that room on that day where we were a young couple with two very young children and the impact and consequence of that diagnosis couldn't be more significant in relation to our lives. Also, it should be remembered that there was huge fear, stigma and the prospect of ostracisation associated with such a diagnosis. **Exhibit WITN1046006.**
19. More significantly, the restrictions that were to apply meant in effect that Gary was to be ostracised within his own family. He was not to sleep with me, we were to sleep in separate beds which was to be the end of our physical relationship. All his clothes were to be washed separately. He was to be given a special diet which was a protein rich diet. Gary's toothbrush was to be kept separate and away from our young daughter who was then aged 2 1/2 years. She was not to kiss him as there was a risk of cross infection through cracked lips. Gary's combs were not to be used by anyone else in the household.
20. In short, it was indicated that Gary was to have nothing to do with his own children.
21. When Gary would treat himself with his Factor VIII treatment, he would be required to insert an injection into his arm and if the children came near him during that process he would tell them in a calm way that he would be finished soon.
22. The next calamity that Gary experienced was a Hepatitis C virus diagnosis. From review of his medical notes, I do not know if Gary knew that he was being tested for the virus in 1994 as it states that he was positive then, however that diagnosis

occurred 3 years later at The Oxford Radcliff Hospital in 1997. **Exhibit WITN1046007.**

23. I recall Gary indicating "Oh what the bloody hell now and what more can they do to me." His viewpoint was very straightforward in that he took the blood products to save his life and the treatment that was intended to save his life ended up causing HIV and Hepatitis C where it was supposed to save his life.

24. Eventually that treatment took his life.

Section 3: Other Infections

N/A

Section 4: Consent

25. I am not sure. Gary was on some trials for research as the team said "you have proved us wrong", this was because Gary had lived a long time. The length of life given was 7 years. The treatment and diagnosis' delivered to us over the years were never fully explained to us.

Section 5: Impact

26. The advice that we received was absolute isolation within the home in circumstances where we couldn't tell anyone about what was occurring. Also we were coming to terms with an appalling, life-threatening and terminal illness.

27. The only reason we survived these pressures was that we knew as a couple that we had to be strong for each other and most especially for our two very young children. Gary was adamant that he would beat it and survive to see the children reared. That strength of character carried us through what was the most devastating period that could occur for any couple.

28. The media sensationalistic approach that occurred in relation to AIDS and HIV infection created its own pressure in that one did not wish to be discovered. We lived a life in fear of discovery and also absolute intent on ensuring preservation of anonymity and confidentiality in relation to Gary's circumstances.

29. During all of these years, Gary continued to work and provide for our family. Although he would have had health issues, he was determined to earn to support, to ensure that every opportunity was afforded to his two children.
30. We made a conscious decision not to have any further children although we would have liked to have had more children, as we didn't know whether one or both of us would survive to see any children to maturity. Also it should be remembered that after Gary's diagnosis I required to be tested when I knew that if I turned out to be HIV positive that one or other or both of our children would also be HIV infected. That is an appalling position to find yourself in when you know that you could potentially be responsible for the infection unintentionally of your own children. Waiting for that result was a very difficult period on a personal level for both of us. The wait for that test result was three weeks, every day was a day of worry, anxiety and fear as to what that result might bring.
31. Up until the date of Gary's HIV diagnosis, he was open in relation to his Haemophilia condition and if asked why he was disabled or exhibited lameness or an awkward gait, he would respond that he was a Haemophiliac. Having disclosed that information, after Gary's HIV diagnosis, we started to analyse as to who Gary had told about his Haemophilia condition as we feared that such persons could put two and two together and guess that he was HIV positive. After Gary's HIV diagnosis, if someone asked him about his unusual gait, he would answer that he had bad arthritis, which to some extent was accurate.
32. Yet, it obviously was realised in the Community that Gary was a person with Haemophilia and possibly that he had developed AIDS. Then the notes started coming through the letterbox with the words "AIDS" on them, "Scum". In addition, notes came through with "Homo", "Homosexual" etc. Even on one occasion, dog faeces was put through the letterbox.
33. No greater sense of social isolation, ostracisation and condemnation by a community can occur to any family than what occurred to us during that time.
34. It emphasised Gary's illness, his different situation, exacerbated our fears and caused huge concerns in relation to our children's welfare.

35. Within one year of Gary's diagnosis, his very good friend [GRO-A] also a Haemophiliac died from the consequences of AIDS. [GRO-A] family had suffered awfully in terms of social abuse similar to what we experienced and that family on his death moved away from their home.
36. [GRO-A] death, what happened to that family and indeed our own experiences put the fear of God into us as to what would happen to our family.
37. People would still ask "has Gary Haemophilia" and then rapidly ask "has he got AIDS." One was constantly on one's guard not to disclose what was the most sensitive secret capable of maintaining. I didn't even tell my 5 brothers and sisters of Gary's HIV status. It was an absolute secret to be protected at all costs.
38. Gary continued to soldier on and continued to work and we put plans in place for our retirement. Gary was diagnosed as being Hepatitis C positive in or around 1997. I can pinpoint the time period as to where we were living at the relevant time. I now realise that that particular diagnosis was extremely late in that the first Hepatitis C test result had been approved by Chiron Corporation in 1989. I now wonder as to why it took so long for Gary to be informed of his Hepatitis C status. I would have expected that during the course of the early 90s at the latest, that Gary would have known about his Hepatitis C infection. I presume that for many years he would have exhibited abnormal liver function test results which would have been suggestive of the prospect of Hepatitis C infection. See WITN1046007 above.
39. Gary managed to live sufficiently long to be able to avail of the Triple Therapy options for HIV infection that materialised. Some of those treatments had side effects including diarrhoea, nausea, sweats, sleep disturbance and weight loss. Although these treatments preserved life, they didn't automatically preserve quality of life. In addition, there was a problem in terms of lipodystrophic effects relating to lipid redistribution necessitating the prescription of Statins to deal with the cholesterol consequences that might occur from same. Gary's appearance changed, presumably due to fat redistribution arising from the treatments concerned. It no longer was the same Gary in appearance that I knew for the early part of our life together. **Exhibit WITN1046008.**
40. The next issue which was equally horrific was Pegylated Interferon and Ribavirin treatment for Hepatitis C infection. Gary started on his Pegylated Interferon/Ribavirin

course of treatment on 20th May 2003 and ceased that treatment on 4th November 2003. During that treatment, he was also on therapy for his HIV infection. He did not receive a prophylactic antidepressant to blunt the side effects of the Pegylated Interferon/Ribavirin treatment prior to commencement of same. He suffered the most awful mood changes, personality change and indeed was severely depressed during the course of the treatment. He suffered various physical consequences including hair loss, weight loss, nausea, vomiting, night sweats and all of the side effects that exist in relation to this treatment option. **Exhibit WITN1046009.**

41. Gary was a real pleasant, gentle personality but he changed into a grumpy, depressed, sad individual. Treatment caused this effect. We did not realise that this would occur, and we were ill-prepared for that consequence. It is difficult to assist somebody who is receiving the most horrific type treatments if one does not understand the true consequences in relation to those treatments and their side effects.
42. The treatment for Hepatitis C infection was successful to the extent that it eliminated the Hepatitis C virus. Yet it did not remove the consequences of that virus in that Gary continued after treatment to suffer significant tiredness.
43. Also Gary was a person who believed that his Hepatitis C condition had been eradicated. Unfortunately, that condition came back in a very different guise to cause Gary's death.
44. I believe that Gary succumbed to the effects of liver cancer, I received a letter to that effect that supported an application subsequent to Gary's death to the Skipton Fund. I am extremely concerned that during the period 2003 to 2010, that there was a failure on the part of the Hospital Authorities to properly monitor Gary's situation in respect of the prospect of cancer and more particularly liver cancers. I fear that the opportunity was missed to diagnose in an early manner Gary's liver tumour situation to allow the prospects that then existed for both radiotherapy/chemotherapy treatment combined with excision of said liver tumours. That issue haunts me to this day as I believe that if I had of been attending with Gary in the periods leading up to his eventual diagnosis that I might have exerted sufficient influence upon the Hospital personnel to ensure that all necessary tests were undertaken. Gary was much more of a reactive personality in terms of his ongoing healthcare where I took a much more

proactive approach and would generally send him off with a list of questions to be asked of the doctors. My attitude was derived from my auxiliary nursing background and my understanding of how to some extent the Hospital system worked.

45. From 2005 onwards, we started to put in place our retirement plans and acquired a property for dog kennels and we intended to undertake boarding and doggie day care. For the first two years, we undertook the necessary work to prepare the business including obtaining Planning Permissions etc. Gary continued to work at Bedford Hospital and travelled home at weekends to assist with the endeavour concerned.

46. In 2007, Gary retired, and we looked forward to the prospect of a joint venture together that would support us in our formal retirement. We didn't realise that that period of time would be short together. On GRO-C 2010, Gary was admitted to Hospital in circumstances where he was diagnosed with liver cancer and died on GRO-C GRO-C 2010. The period that we had available for preparation of Gary's loss was very limited and I question as to whether even at such a late time in Gary's life or healthcare, a further medical mistake occurred. **Exhibit WITN1046010.**

47. Gary's death meant the end of our business, I sold up and moved on and elsewhere.

48. I make this Statement for the benefit of my son Matthew, my daughter Sarah and my grandchildren. It should be remembered that Haemophilia is a hereditary condition. I have a grandson now who has severe Haemophilia A and I earnestly wish that the catastrophe that befell both Gary and our family must be avoided for future generations. No family deserves to suffer in the manner in which we have suffered. Also, I don't wish a situation to occur where my grandchild has anything but optimal treatment.

Section 6: Treatment/Care/Support

49. There was no support initially from GRO-D Hospital, no counselling, no psychological support, no information.

50. Eventually, Gary attended Oxford and more particularly the Churchill Hospital. He met a lady, Mary Fletcher, who was a Social Worker and received some information in relation to HIV so that we had some understanding of the condition itself.

Section 7: Financial Assistance

51. Gary received monthly payments from MacFarlane Trust, also stage 1 from Skipton. When Gary passed I received a monthly payment for 9 months and payment towards his funeral. I was denied any future payments because I lived with my son and family, so as it was means tested. I haven't received anything since.

Section 8: Other Issues

52. Gary attended the Hemophilia Centre and Mr. Conlan at Oxford Hospital Churchill every 4 months. His last appointment was GRO-C 2010, he was diagnosed with cancer GRO-C 2010. He passed away 3 weeks after diagnoses on the GRO-C 2010.

53. I feel very strongly that Gary should have had tests and scans from time to time. I feel they didn't keep a close enough eye on him. It all happened very suddenly at the time when he died, he was diagnosed on GRO-C 2010 and died GRO-C 2010. I feel it was neglect from the professionals at GRO-D hospital. They did not scan his liver as routine after he was told he had 'got rid' of the Hepatitis C.

54. The issues upon which I believe this Inquiry should focus relevant to my husband Gary are as follows: -

55. Why was Gary not informed of the risk of the U.S. plasma derived factor concentrates which he received i.e. that same could transmit viral infections?

56. Why was the treatment changed during the period of high risk with HIV infection from Factor VIII concentrates to alternative treatment options such as cryoprecipitate as occurred in other countries?

57. Why was there an educational campaign undertaken by the Department of Health that created hysteria to the extent that we were ostracised in our community?

58. Why was there not a focus on informing both patients and their families of the true extent of side effects of treatments for viral infections? If we had been better informed, we would have been better able to assist Gary in coming to terms with the side effects of those treatments.

59. Why did the Hospital decide not to continue to monitor Gary for the risk of liver cancer subsequent to his achieving a sustained viral response in relation to Hepatitis C infection? The failure to monitor meant that when he was diagnosed he was at end stage of life. That failure to monitor resulted, we believe, in an inability to treat the liver tumour that existed.

60. The NHS ought to be required arising out of the consequences of this health scandal or catastrophe to ensure at all times that the Haemophilia population receives optimum treatment as early as it becomes available. I urge that recommendation to you as Chairperson of this Inquiry on the basis that I want to protect my grandchild from the consequences that befell my husband and caused his untimely death.

61. I deliver this Statement to the Infected Blood Inquiry for the benefit of my family, the Haemophilia Community and Society to ensure that the Healthcare system can be improved arising out of the lessons and mistakes of the past.

Statement of Truth

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

Signed

GRO-C

Helen Northwood

Dated

13th OCTOBER 2021.