Witness Name: DEBORAH SMITH
Statement No: WITN5655001
Exhibits: 0
Dated: May 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DEBORAH SMITH

I, DEBORAH SMITH, will say as follows: -

Section 1. Introduction

1. My full name is Deborah Jane Smith. I was born on GRO-C 1964 and I live at GRO-C, Somerset GRO-C.

2. My ex-husband, Gary Tonks (born on GRO-C 1958), was infected with the Hepatitis C Virus (HCV) through contaminated blood products. He died, having developed prostate and liver cancer, on 18th January 2015, aged 56.

3. This witness statement has been prepared without the benefit of access to Gary's medical records.

Section 2. How affected

4. Gary has mild Haemophilia A with a clotting factor of 15%. He was the first known haemophiliac in the family, diagnosed at 5 years old. He always told me that his clotting factor was 15%, but I didn't understand much about it at all. It didn't initially affect us in any way.

5. Gary was under the care of the Birmingham Haemophilia Centre initially at the Children's Hospital and then at the Queen Elizabeth Hospital (QEH) in adulthood. He attended at the Centre for his (what I remember to be annual) routine appointments. He very rarely needed treatment.

6. Gary believed (as I did) that he became infected with HCV through a batch of Factor VIII (FVIII) concentrate administered to him at the QEH in 1984/1985 (before we were married in June 1986). He hadn't needed treatment for years before that. In fact, he was in his mid-teens when he needed previous treatment and he didn't need any more treatment until after he was told that he had been infected with HCV in the late 1980s.

7. The treatment Gary had in 1984/85 was the first (and last) time I saw Gary having FVIII treatment and the memory of it is now ingrained on me. I remember watching Gary through a door window as he was sat on a hospital bed with the doctor straining to push it in. I was with Gary on my leave from the army when Gary had a fierce nosebleed. I watched him have the FVIII concentrate at the QEH without knowing what was going to happen further down the line. After we were told of the HCV diagnosis, I was never again able to witness Gary having it. I still think of Gary every day and I find it shocking that it was a mere nosebleed that ultimately resulted in his death.

8. Gary was not given any information or advice about the risk or possibility of infection from FVIII concentrate before he had the treatment. We were married and had moved down to GRO-C when Gary was told by a Consultant at the Haematology Department at the Musgrove Park Hospital, several years later, that he was infected with HCV. I remember Gary returning from a routine appointment there to tell me that we both needed blood tests to check that we didn't have HIV/AIDS and hepatitis (through contaminated blood treatment). I wasn't sure what to make of it. My first thought was 'what has he been doing/has he cheated?' and we had a row about it. I remember it being a few weeks before we had the results and we were on tenterhooks waiting. I remember the feeling of relief to find out that neither of us were infected with HIV but that Gary (alone) was infected with HCV.

9. We were not given adequate information to help us understand and/or manage Gary's HCV infection. I didn't know what it was. We were under the impression that (compared to the possibility of having been infected with HIV) it was nothing we should worry about.

Section 3. Other Infections

10. I do not believe that Gary was infected with anything other than HCV.

Section 4. Consent

11. I do not think that Gary was tested without his consent. He was treated with FVIII concentrate without full and/or adequate information. The clinicians knew that the blood products were contaminated and yet they did nothing about it. It didn't just affect haemophiliacs but all their loved ones too. Gary was subsequently offered Interferon treatment as part of a trial. I think he realised at that point that life was going to be short for him. Gary and I were the best of friends (even after

we divorced) and we spoke at least every other day. Our children are left devastated by what happened to their father and are GRO-C to do so, but I promised Gary myself that I would fight for him after he had gone.

Section 5. Impact of the Infection

12. I met Gary through a family friend of a friend when I was just 14 years old. He was 6 years older and was always my starry-eyed crush. After sitting with him at a huge family dinner, I remember telling my parents that night that I had met the man I was going to marry. I subsequently went into the army and Gary went to College to study Art, and we were friends in between, but we got together at a friend's wedding when I was 19 years old and Gary was 25 years old. As stated, we married in June 1986.

13. The HIV and HCV tests, we had in the late 1980s, caused a huge issue for both of us. We had been trying for a baby without any prospect of success and had just tried to go down the IVF route. The tests were on our records and the IVF was denied. Our medical records were scrutinised every which way we turned with heart-breaking results. I remember the whole thing vividly as I was told that I would have to abort a boy should I happen to conceive, and I would be subjected to a lot of conditions to be allowed to keep a girl. We then had to go down the adoption route but there was so much in the press associating haemophilia with HIV/AIDS that (together with Gary's HCV) diagnosis we were blocked a couple of times from adopting before being allowed to adopt our daughter, Sophie, in 1990 at four weeks old.

14. After Sophie, we were told that adoption would no longer be available to us. Adoption placements for disabled children and those with special needs are harder to find. We had a hard fight to adopt our son, Mitchell, and it was only through him GRO-C and fewer restrictions that we were finally allowed to adopt him in 1995. Mitchell is GRO-C

15. Gary and I were under terrible financial strain. We need to move for more space and an extra bedroom after adopting Mitchell. We couldn't obtain a mortgage to be able to move without life insurance. Our life insurance went from £75 to £1,760 per month after Gary's HCV diagnosis. It was more than Gary earned and we were never able to obtain life insurance again. We had to raise two children in a two-bedroom house that was far too small for us. It was a nightmare and extremely hard on Sophie having to share a bedroom with a younger brother, particularly once she hit puberty.

16. Gary didn't feel well and was tired and lethargic all the time. In or around 2000, Gary was asked to take part in a trial in an attempt to treat his HCV. Gary had to inject Interferon into his own stomach every week over a 12 month period. We ran a military business selling hiking and camping gear. Gary was fatigued enough without the treatment and during the treatment he could barely work at all. We were under a terrible strain and ended up going bankrupt. Gary then went back to doing some kitchen design work for a few different companies before ultimately taking a very lowly paid job (earning less than £1,500 per month) as a SSI Senior Staff Instructor.

17. Gary was a loving and attentive husband and father. He loved nothing more than teaching history to the children at weekends and on our holidays in the UK and abroad visiting places of historical interest. The Interferon treatment had a massive effect on him. He changed from a lovely, happy go lucky family man to being insular, selfish, aggressive and abusive. After the Interferon kicked in, Gary became obsessed with the Air Cadets and spent most weekends away with them doing training. He would spend hours each evening on the computer or the phone chatting to other members sorting weekends and training for both the cadets and adults. He would help the cadets and staff as much as he could but didn't have time for his own children's homework and all time away, including holidays, had to be worked around cadet activities and events. I had to take all

the strain of helping a child with GRO-C on my own which was hard and divided our family. All of Michell's GRO-C are long standing and he is dealing with them still to this day. His understanding of how his dad was at that time is clear in his mind, and gave him a thought that his dad didn't care for him as much as he did for the cadets which is heart breaking to hear as Gary loved his kids but he changed. As Gary did more, he rose fast in the cadet organisation and he became the top Warrant Officer within the UK. This gave Gary the power that he seemed to thrive on. He often said that we didn't give him that, which was also hard to hear from someone you loved.

18. The change in Gary when the Interferon took hold was profound and his aggression worsened. He would fly off the handle for the smallest thing and could change the atmosphere in a room from happy and fun into silence in a second, like the flick of a switch. At his worst point, he had my 78 year old grandmother round the throat because she had put sugar in his coffee and I was left feeling bereft. I had no idea that Interferon could cause such a dramatic change in a person. The nastiness really was the worst thing to happen to Gary. The Interferon cleared the HCV but when he developed prostate cancer things became progressively worse and after 35 years, I just could not cope with the stress of how Gary was behaving with the mental strain of constantly trying to think 2, 3 or 4 steps ahead of him all the time, to try to pre-empt any issues he might have or to try to stop him getting cross or angry. I had no choice but to let Gary lead the life he wanted to leave. My mental strain has never really recovered from then. It is better but this time has left me with a constant fear of trying to appease people. I left with Mitchell to a small rental flat down the road and Sophie went to live with her boyfriend of the time. What happened to Gary ripped our family to pieces. I know he still loved me and I still love him and will do to my dying day, but we just couldn't make it work which is my biggest failure. Gary is never far from my mind and he will always be what was my childhood sweetheart. He was the man I wanted above everything else to spend my life

with and because of what HCV had left us with all our dreams gone and that is something I don't think I can ever forgive.

19. Gary knew he wasn't well but didn't know why he wasn't well. When he was given the cancer diagnosis, it was too far gone, and it was spreading too quickly to do anything about it.

20. Sophie was distraught when she lost her father. She (like me) met her partner at aged 14. She always wanted the big fairy tale wedding with her father walking her down the aisle. She no longer wants any of that. She has had a little boy and she is suffering as he will never know his grandfather. Mitchell is very cynical about his dad and really does not like the Air Cadets as he feels it took his dad away from him. He knows his dad loved him but there is always a 'but' when he says that.

21. I have since remarried and I am happy, and it is only now that I can fully understand how bad things had become and how far reaching, unnecessary and unfair it all was. Gary couldn't help the change in his behaviour, and it destroyed our marriage. Gary and I had a friendly and amicable relationship despite everything. We had the same circle of friends and that didn't change. I still think of him every day. I lost both my parents when I was aged 21, so Gary's Mum and Dad were my substitute parents for most of my life. I felt that was lost when we split up. What happened to Gary destroyed his parents and they cannot talk about it to this day. It ruined our family, our marriage, Gary's parents and grandparents as well as Gary's children and grandchildren. Everyone involved should own up and take responsibility for the pain they have caused so many people.

Section 6. Treatment/care/support

22. Gary and I had no counselling or support. Sophie needed bereavement counselling after Gary's death. She took her father to his cancer appointments (at the same hospital she worked) and helped him with his personal care. She was left traumatised and still has major issues. She took two to three months off work when her father passed (as it was too upsetting for her to return to that hospital) and ultimately had to give up her job for one at a lower level than her qualification. Every birthday, death anniversary and Christmas has dragged Sophie down. It is only in the last 12 to 18 months that she has started to pick up, but she has lost her Dad and he can never ever be replaced. Sophie's mental strain has made her now less able to cope with any stress. She finds it extremely difficult and feels this is because of what she had to go through with her dad. This in turn has affected her earning power and is now on a much lower scale than she was before. She knows she will never be able to do the same job as she did before, and this also is upsetting. She would like you to know she misses her dad every single day and finds the fact that her dad will never know his grandson heart breaking.

Section 7. Financial Assistance

23. We received a £20,000 payment through the Skipton Fund in the early 2000s and nothing else.

Anonymity, disclosure and redaction

24. I am not seeking anonymity and understand this Statement will be published for the purposes of the Infected Blood Inquiry.

Statement of Truth

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

GRO-C

Signed…………………

Dated…16th June 2021………..