

Witness Name: JOSIE QUIN

Statement No: WITN4656001

Exhibits: WITN4656002

Dated: AUGUST 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JOSIE QUIN

I, Josie Quin, will say as follows:-

Section 1. Introduction

1. My name is Josie Quin. I was born on **GRO-C** 1973 and I live at **GRO-C**
GRO-C
2. My father, Andrew Quin (born on **GRO-C** 1950), was infected with the Hepatitis C Virus (HCV) through a transfusion of contaminated blood plasma and/or units of blood at Crawley Hospital in the 1980s. He died of Liver Cirrhosis and Mantle Cell Lymphoma on 16th May 2020, aged 69.
3. This witness statement has been prepared without the benefit of access to my father's medical records.

Section 2. How infected

4. My father had Ulcerative Colitis and was in and out of hospital annually and bi-annually from 1973 through to 1995. My father received blood plasma and units of blood whilst being treated for dehydration and hemorrhaging at

Crawley Hospital in the 1980s. Crawley Hospital have since lost my father's medical records (and apparently those of my mother, despite the fact that my mother gave birth to me and my younger sister at Crawley Hospital) and therefore I do not have the exact dates of my father's treatment. Stage 1 and Stage 2 ex gratia payments have been made through the Skipton Fund.

5. No information or advice was given to my father about the risk of being exposed to infection. My father felt unwell after having an Intestinal Ileostomy operation in October 1995. He researched/read up on the symptoms he was having (in the Guardian newspaper I believe) and recognised that they were a match to the very same symptoms of HCV. Prior to that, despite the Ulcerative Colitis and frequent visits to Crawley Hospital, my father had been a fit and active man who enjoyed outdoor pursuits. At my father's request, his GP tested him for HCV and the test confirmed that he was HCV positive in October 1996. I refer to the Exhibit marked **WITN4656002** being a photo of me and my father taken a couple of months before his operation and just over a year before his HCV diagnosis. A few months after this photograph was taken his life would change forever.
6. Very little/inadequate information was provided to my father to help him understand and manage the infection. No counselling or treatment was offered to my father at that time but he was referred to the Royal Free Hospital in London where he was initially told that he may only have a few years to live. There was no cure at that time and other than being offered pain relief and antidepressants, my father was pretty much left to manage his symptoms and the resulting chronic depression by himself. My father battled with the virus for a further 24 years before recently dying of Mantle Cell Lymphoma and Liver Cirrhosis.

Section 3. Other Infections

7. I do not believe my father was infected with anything other than HCV.

Section 4. Consent

8. At the time of the blood and plasma transfusions my father had no reason to believe that he was at risk of infection. He was not warned of the potential risk.

Section 5. Impact of the Infection

9. I have an older brother and a younger sister. My family and I were devastated as my father was told that he only had a few years to live at best. We expected that he would die imminently. It was like being given a death sentence. We spent every day of the next 24 years expecting my father to die and preparing for that day. I had a son at the age of 22 and my relationship with my son's father unfortunately did not work out and I subsequently became a single parent. My father became a father figure to my son. My son adored my father and relied utterly upon him for support and guidance and so to lose his grandfather this year has been like losing a father to my son, as well as me and my siblings actually losing a father.
10. My father ran his own car mechanic business in the mid to late 1980s and then he worked as a chauffeur. After his Ileostomy operation and his HCV diagnosis, my father became too ill to work. Shortly thereafter my mother was forced to give up her job as a Post Office Clerk in order to care for my father, at which stage my parents had to rely on Benefits which meant we all suffered financially. My father's quality of life suffered enormously which impacted on the whole family as we were not able to do all the family activities we once did. My parents were never able to buy their own home or help their children financially etc.
11. The stigma associated with HCV was terrible. No-one was aware of the NHS blood scandal at that time. I told some of my friends that my father had contracted HCV and they would say inappropriate and hurtful things to me like 'You get that from sleeping around, don't you?' and 'You get that from using

drugs and needles, don't you?'. I felt like I couldn't then tell anyone about my father's illness as a result. We even kept it a secret from some of our own family members.

12. My father suffered with chronic fatigue. He was constantly tired and drained of strength and energy and would have to pace himself in order to make it through each day. He could only stay awake for a few hours at a time before needing to lie down and sleep for an hour or so. Despite feeling exhausted all the time, he suffered with insomnia due to the fact that he felt so uncomfortable and ill and suffered from nightmares, hot sweats and fever. My father described the sleep he experienced as a 'dirty sleep' and he dreaded the night time. He suffered with flu like symptoms and joint problems. He also suffered with nausea and stomach bloating which had a major impact on his appetite and diet. He had very little appetite because of the discomfort he experienced after eating and could only eat certain foods that he could easily digest. This restricted diet caused considerable weight loss towards the end of his life. He suffered with brain fog and poor memory. As stated above, my father also suffered with chronic depression post his Ileostomy operation and HCV diagnosis.

13. Despite all this, my father was a tough customer. He would soldier on and would never complain. We used to go on holiday to a farm in Devon as my parents enjoyed camping and caravanning. The journey would take a terrible toll on my father with regular stops on the way as he couldn't manage a five hour trip without having to take regular breaks to sleep. At the beach he would spend most of the time in the car and occasionally come down to the beach to say 'hello'. My father struggled in the heat as he was often burning up and would be drenched with sweat from doing the smallest of tasks. His illness simply prevented him from participating in activities, he just found it all too draining on the little energy and strength he had.

14. My father had bad lungs and chronic asthma during childhood which he grew out of but after his Ileostomy operation in 1996, his asthma came back with a vengeance. He developed glaucoma and so his eyes were always bloodshot

and sore, needing daily eye drops and regular hospital appointments. My father's stomach would often flare up causing him a great deal of pain and discomfort. His skin was like paper and would bleed from a mere scratch. He developed fungal nail infections. His teeth had started to rot and 2 of his (hollow) teeth fell out. His body was shot to pieces but he always had a decent head of hair, took a pride in his appearance and tried to stay positive to the end. He had such determination to keep going that just two weeks before he died, with our help, he rode his bike up and down our road in an attempt to try to stay fit. He was so brave and an example to us all.

15. My father tried to apply for HCV clearing treatment (Pegylated Interferon and Ribavirin). We had to fight hard to get this treatment and were forced to make an appeal on local television. My father was finally offered the treatment but unfortunately, during treatment, he suffered a mild heart attack and wasn't well enough to complete the treatment. My father had his second (and unsuccessful) attempt at clearing HCV with Harvoni in the Spring of 2018. Yet again, we found out about the treatment ourselves by researching it online. We believe the Harvoni treatment may have caused the Mantle Cell Lymphoma as one of the side effects. This side effect was not disclosed to my father prior to him having the Harvoni treatment although they kept checking his lymph nodes throughout the treatment. I remember my father saying that he would never have had the treatment had he known there was a risk of Lymphoma.

Section 6. Treatment/care/support

16. Some of the obstacles my father faced in obtaining treatment are set out in paragraph 16 above. He was told before the Intestinal Ileostomy in October 1995 that he would be fit and well after the operation and be able to return to work and live a normal life but this couldn't have been further from the truth. After being diagnosed with HCV my father had to travel by train, to and from hospitals in London, including the Royal Free and due to the distance and time it took to complete the journey, it was a huge ordeal for him and my

mother. He was let down at every stage. He has had to fight all the way through for treatment and support and has often been ill advised, given false information and been kept in the dark regarding new treatments and financial support. When he was diagnosed with lymphoma, he was unable to have chemotherapy because of the poor state of his liver and he was also advised that the chemotherapy would flare up the HCV, and so he kept the Lymphoma under control with nutrition and natural therapies and managed to carry on for a further two years before his death in May 2020. My father took good care of himself throughout his life. He never smoked or drank. His own father had been an alcoholic and so my father had a real aversion to alcohol. I feel like the whole issue of contaminated blood has been brushed under the carpet and kept out of the public eye, in the hope that it would just go away.

17. No members of my family were ever offered any counselling or support.

Section 7. Financial Assistance

16 My father found out about the Caxton Foundation and the Skipton Fund himself, through his own enquiries. He received the Stage 1 ex gratia payment albeit he had to fight for this payment by way of providing witness statements from people who saw him in hospital receiving blood in the 1980's, including a witness statement from the hospital Vicar. He began receiving regular payments from in or around 2017.

17 Prior to 2017 my dad applied for and received grants to help with the purchase of household items that could not be afforded on Disability Living Allowance and Incapacity Benefit alone. Payments were for a new bed, a sofa and a deposit for a Motability vehicle.

18 My father later received the Stage 2 ex gratia payment having had to prove that the HCV had caused severe liver cirrhosis, which I find appalling. It should have been enough that my father had been infected in the first place. He should not have been practically dying before they awarded him the Stage 2 pay out.

Anonymity, disclosure and redaction

19. I am not seeking anonymity and I understand that this Statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed

GRO-C

Dated.....

9-9-2020