Witness Name: Ira Hill
Statement No: WITN7431001
Exhibits: 0
Dated: October 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF IRA HILL

I, Ira Hill, will say as follows:-

Section 1. Introduction

1. My full name is Ira Rees Hill. I was born on GRO-C 1965, and I live at GRO-C GRO-C Northamptonshire GRO-C.

2. My husband, Stephen John Hill (born GRO-C 1956), was infected with the Hepatitis C Virus through a contaminated blood transfusion. He died on 8th September 2014 due to Hepatocellular cancer, aged 58.

3. I am a widow and have lived alone since Stephen (Steve) died. I retired from being employed in the NHS as a mental health nurse in 2020 and now spend my time walking with the local ramblers, spending time with family and friends, I am a magistrate in the family courts and enjoy looking after my grandchildren. I have one daughter who lives locally with her husband and two young daughters, and I see them most weeks which is very special to me. However, I am incredibly lonely living alone and find that the retirement and later life I had

hoped and planned for with Steve wasn't to be as Steve died prematurely due to an infected blood transfusion.

4. Steve received a contaminated blood transfusion during an operation on his back in the early 1990's at Kettering General Hospital and was later diagnosed with the Hepatitis C Virus in approximately 1995. The natural progression of the Hepatitis C Virus continued after several failed treatments at Oxford, with Steve being diagnosed with Hepatocellular cancer in 2011.

5. This witness statement has been prepared without the benefit of access to Steve's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

6. Steve was my husband for 25 years before he died in 2014. We were very happy together and enjoyed each other's company. Steve was a quite gentle man who had a steady influence over our lives and contributed financially to the household as a qualified bookbinder. Steve also contributed to our household and that of our daughters as he was keen and competent at DIY and undertook the more regular tasks needed around both households. Steve was very knowledgeable on a wide range of topics and enjoyed entering quizzes with his friends, was a volunteer at the local rugby club where he was club secretary and, when physically able, he was a keen walker and enjoyed regular walking trips to the Lake District.

7. Steve injured his back in 1989 and was seen by a local consultant who agreed to undertake a fusion operation after steroid injections had failed to relieve the ongoing pain he experienced. Steve undertook the surgery during the summer in either 1991 or 1992. During the operation I received a phone call asking what Steve's usual pulse rate was, as they were concerned for him as his pulse rate was very low. I replied that his pulse rate is always very low and was

informed verbally afterwards that it was due to a perceived low pulse rate that resulted in Steve receiving a blood transfusion during the operation.

8. Steve attended the GP in about 1995 as he had sinus problems and was referred to an ear nose and throat specialist. This specialist requested a range of blood tests to be undertaken and when Steve met with this specialist for a follow up appointment on his own, he came home and informed me that there was nothing wrong with his sinuses but that he was infected with the Hepatitis C Virus. Steve was totally unaware of what the Hepatitis C Virus was and the implications. As a nurse I was aware and from that point onwards I have been greatly and irreversibly impacted by the Hepatitis C Virus and the ill health and then death of my husband.

9. Soon after receiving the diagnosis of being infected with the Hepatitis C Virus Steve was referred to the Oxford John Radcliffe Hospital where a consultant Dr Collier tried to clear the Hepatitis C Virus with courses of Interferon and Ribavirin which despite very difficult side effects, were unsuccessful. Steve was therefore screened by ultrasound six monthly for any changes in his liver and in June 2011 a tumour was detected and confirmed to be Hepatocellular Carcinoma.

10. Steve's care was transferred to Addenbrookes Hospital in Cambridge under Dr Alexander's team to undertake an assessment of suitability for a liver transplant. In August 2011 Dr Alexander confirmed Steve's suitability to go on the transplant list in addition to Steve undertaking several ablations and embolization's in attempts to prevent the growth and spread of the cancer. After fully complying with all the restrictions of being on a transplant list for just over a year which included not being able to attend my mother's funeral as it was over two hours away, Steve was removed from the transplant list on the 17th July 2012.

11. Steve was then referred to Dr Collier, an Oncologist at Addenbrookes where he was initially treated with Soranfenib which commenced on the 7th September

2012 after receiving funding approval. This period was a turbulent time for Steve as the side effects on this medication were extremely difficult to tolerate and were painful and distressing. Soranfenib was stopped in August 2013 due to increase in size of tumours and complex and toxic side effects.

12. Steve was then referred to a drug trial based on London University Hospital under the care of Dr Myer. Steve was accepted onto the trial and again was exposed to a drug regime that resulted in a wide range of side effects with weekly appointments in London as part of the trial structure. Steve undertook a scan in London when the results showed that the tumour had grown and was causing pressure on the portal vein. Due to this progression of the cancer Steve could no longer participate in the trial and was referred for Palliative care in Northampton under the care of Dr Riley on 18th June 2014.

13. Throughout all these treatments and procedures Steve remained on the surface optimistic, determined, and compliant. In conversations with Steve, I was very aware that underneath he was distressed, frightened and fearful for his own and his family's future. This type of distress cannot be calculated or dispelled however Steve was able to communicate his needs with dignity, respect and compassion for others.

14. The palliative care Steve received in Northampton was mainly about reducing the impact of any symptoms which were increasing in severity, pain levels and complexity. Steve had a number of admissions to Northampton and Kettering hospitals in order to treat dangerous symptoms. From 1st September 2014 Steve deteriorated rapidly and he died at home on 8th September 2014.

15. My view as of the manner in which the Hepatitis C Virus diagnosis was communicated to Steve is a very poor one. Steve was totally unaware of what Hepatitis C was and the implications and had not known that he was to be tested for this virus. Steve was unaware at this point of what the treatment options were, the potential physical impact of the infection, the stigma attached to this infection at the time and the potential consequence of dying prematurely.

16. Steve described the way in which he was given the Hepatitis C diagnosis as being delivered in a cold and unsupportive manner. It was delivered without giving any information about the impact this diagnosis may have on an individual and their family's life going forward, the nature of any treatment and the possibility that the treatments didn't always lead to the individual being infection/virus free.

17. Steve was not given any information about how to prevent the spread of this infection until he was seen at Dr Collier's Clinic in Oxford. Once this information was supplied to Steve, he made changes in order to protect his family ie keeping his toothbrush away from mine and our daughter's.

18. I consider that Steve should have been given more detailed information, support and advice when first diagnosed as having Hepatitis C by the Ear, Nose and Throat Consultant. In addition, Steve should have been informed that he was being tested for Hepatitis C virus and why prior to the blood test being taken.

Section 3. Other Infections

19. I don't believe that Steve received any other infection other than the Hepatitis C Virus.

Section 4. Consent

20. Steve injured his back in 1989 and was seen by consultant at Kettering General Hospital who agreed to undertake a fusion operation after steroid injections had failed to relieve the high levels of ongoing pain experienced by Steve. Steve undertook the back surgery in either 1991 or 1992. During the operation I received a phone call asking what Steve's usual pulse rate was, as they were

concerned for him as his pulse rate was very low. I replied that his pulse rate is always very low and was informed verbally afterwards that it was due to a perceived low pulse rate that resulted in Steve receiving a blood transfusion during the operation. It was noted at the time that Steve had received a blood transfusion during the operation in order to stabilise his blood pressure and pulse rate. Steve was surprised that he had received a blood transfusion and there was no discussion at the time with professionals that there was any possibility that the blood could have been infected with any disease or virus.

21. I do not know if Steve was given any information or advice about the risks of infection from any blood products as part of the pre-operation consent process. However, this was not a topic of discussion that I was present for as a lead up to the operation during an appointment with the consultant which I attended along with Steve.

22. Steve was tested for Hepatitis C without his knowledge and consent and at the point of returning home having been diagnosed with the Hepatitis C Virus he didn't actually know what it was. Steve had no information about Hepatitis C pre or post the blood test that was undertaken which included the test for Hepatitis C.

Section 5. Impact of the Infection

23. Once diagnosed with Hepatitis C Steve became fully informed about the treatment, prognosis, how to protect his family and support systems in place once he attended Dr Colliers clinic at the John Radcliffe Hospital in Oxford in 1995. Steve undertook any treatments available to him and tolerated the many side effects which were severe. Physically, prior to being diagnosed Steve was suffering from fatigue and repeated and persistent flu like symptoms without knowing why. Once the treatments of Interferon and Ribavirin were commenced to try to eliminate the Hepatitis C Virus, Steve suffered from a wide range of side effects which included extreme fatigue, nausea, loss of weight,

insomnia, sore injection sites, itchy skin, disabling headaches, feeling cold and shivery, aching muscles.

24. The mental impact of being diagnosed with Hepatitis C led to emotional distress for Steve and feelings of frustration and anxiety. Steve would rarely discuss the emotional impact of having a potential life limiting infection/illness as he did not want to distress his family by sharing his feelings. However, Steve did discuss his fears of dying prematurely and how precious his life was and his fears for his family's wellbeing after his premature death which he was convinced that would happen. The emotional impact of struggling to work full time and supporting his family whilst undertaking treatments led to Steve at times having to sleep for long periods and miss out on family celebrations which led to again feelings of distress, anxiety and despair. Steve was a very private man, and I was very aware that when he did share his feelings it was due to the extreme distress that he was experiencing which had become overwhelming.

25. There are a number of summary letters from specialist consultants that Steve was under making reference to Steve contracting the Hepatitis C Virus as being 'likely from a blood transfusion'. Steve always found the unfairness of being given a contaminated blood transfusion so overwhelmingly distressing in that this virus, subsequent illness/cancer and his untimely death could have been prevented.

26. Steve was 58 when he died and had no other illnesses that impacted on his physical and mental wellbeing which contributed to his death.

27. Steve developed a wide range of medical complications and conditions as a result of the Hepatitis C virus which included:-

    Hepatocellular Carcinoma
    Embolisations and Ablations required
    Low platelet count
    Shortness of breath and sustained cough

Recommended Liver Transplant – did not happen as cancer spread outside of liver.
Severe side effects of Soranfenib medication
Infection – raised temperatures, repeated and then continuous antibiotics.
Dehydration
Gastric reflux
Sickness
Diarrhoea
Symptomatic pyrexia
Disturbed sleep
Extreme fatigue
Anorexia
Difficulty swallowing
Generalised aches and pains in back and abdomen
Sustained pain requiring morphine
Toxicity from Sorafenib medication
Grade A Oesophagitis
Duodenitis
Blood clot in portal vein
Ascites - Fluid build up in abdomen requiring frequent drains being inserted
Varices - required repeated endoscopies to put in bands to prevent bleeding

Impact of Treatment

28. Steve accepted and tolerated all treatments and procedures available to him. This included Interferon and Ribavirin in order to treat the Hepatitis C Virus which was not successful despite Steve's total compliance with the treatment regime.

29. Steve developed Hepatocellular Carcinoma as a result of the Hepatitis C virus which led to a number of treatments which included Soranfenib which led to dangerous levels of toxicity so was withdrawn. Steve then entered a cancer drug trial (CC223 phase 1 trial selective mTOR kinase inhibitor) however as the Hepatocellular Carcinoma was not curtailed or eliminated and there was increased disease progression. Steve was discharged from London University Hospital into the care of a Palliative care consultant in Northampton.

30. Steve undertook a range of treatments and medications in attempts to alleviate symptoms and side effects which included a wide range of increasing strength of painkillers, long term use of antibiotics, anti-emetics, anti-diarrhoea, spironolactone, platelets infusions, ablations, embolisations, fluid drains in stomach and end of life care including having a 'do not resuscitate ' in place.

31. There were difficulties in accessing treatments as there was certain criteria needed to be met for access to the transplant list and the drug trial both of which led to delays in order for assessments to be undertaken. In addition, there was a three-week delay in receiving the Soranfenib medication as there was a funding issue which needed to be addressed across geographical boundaries between Cambridge and Northampton in order that Steve could be prescribed this medication.

32. One key area where services were not able to meet Steve's needs was the end of life care he received at home during the last weeks of his life. There were mis-communication, excessive changes and numbers of care staff coming into the home, delays in getting services to become available, lack of qualified staff, untrained care staff, no coordination between acute medical teams and palliative care and no communication between hospital and community staff. This resulted in a desperate time for Steve and his family as services that were acutely required were not forthcoming, conflicting views as to what would be helpful leading to a lack of trust in services and totally contradicting advice regarding treatments planned which added to the lack of trust.

33. I am not aware of any appropriate treatments that Steve was not offered once the Hepatocellular carcinoma was diagnosed. However, the end of life support and care was grossly inadequate and increased anxiety and distress for Steve, my daughter and I and not reduced it.

34. The physical impact on the treatments were extreme in that the side effects of medications were painful, persistent, dangerous and frustrating. Some procedures were invasive and required general and local anaesthetic to undertake. All the procedures had potential serious effects which could be life threatening.

35. Steve knew that the Hepatitis C virus needed to be successfully treated in order that he could safely get on with his life. As the treatments to eradicate the Hepatitis C Virus were not successful, Steve was aware that he could develop liver cancer at any point in the future. Steve experienced heightened anxiety which would peak each time he went to Oxford for a screening scan, and he would not be able to reduce his anxiety until he had the results – this cycle would then build up every 6 months when the screening was due again. The impact on Steve when a screening scan resulted in a diagnosis of hepatocellular Carcinoma was emotional devastation. However, he demonstrated a commitment to himself and his family to fight at every step and tolerate side effects that led to distress, fear, mental pain, and depression. There remained an underlying fear for Steve as he was fully aware that the prognosis was poor and that he would die prematurely if the treatments were not successful. Steve in response to a terminal diagnosed would fluctuate between being angry, sad, denial and accepting.

36. The full impact on Steve being diagnosed with Hepatitis C Virus is complex as it impacts on all areas of life. The relationship which he had with myself his wife changed as he felt that he had put me at risk of being infected as it was not known at the time if Hepatitis C could be passed through normal sexual contact. Steve insisted that I undertook a test which I did, and it was negative and from

then on Steve and I used barrier methods during sexual contact. Steve found this to be distressing as he wanted to express his closeness without barriers.

37. Privately within our home Steve would be able to relax and be himself which would include times when he was exhausted when he slept for long periods. There were times when this would impact on our relationship in a negative way as due to extreme fatigue, I was doing all the tasks within the household leaving Steve feeling redundant, useless, hopeless and an inconvenience. The relationship he had with me changed in other ways in that there were times when Steve felt uncomfortable to ask for help as he wanted to be independent. There were times when he needed assistance to undertake personal care tasks and he felt embarrassed and at time humiliated that he couldn't undertake these tasks independently. Steve did not want me to become his carer despite my reassurances.

38. Socially Steve felt at times to be on the side-lines instead of equal as he couldn't enjoy the occasional pint of beer with his peers and felt that he had to explain why he didn't drink. Socially Steve found it difficult to go into lengthy explanations and was aware that some of his peers were making unfounded and prejudiced assumptions as they didn't have all the information.

39. Steve continued to work full time until he was 55 with a drop down to part time work. This part time schedule didn't happen as Steve was forced to stop working due to the cancer diagnosis and ongoing ill health. Steve then found it difficult not being able to contribute to the household finances. This embarrassed Steve as he didn't want to be a 'kept man' as he was very proud and independent.

40. Steve was very close to our daughter, and they shared such a relaxed, loving and respectful relationship. They had great fun together and shared time together in a fun and enjoyable way with a shared sense of humour. Steve was so proud of his daughter and expressed his love for her in always being emotionally available to her, sharing her troubles, helping her modernise her

first home and supporting all her endeavours. Steve fully supported her marriage and was determined to give her away at their wedding in July 2014 (7 weeks before he died) despite being incredibly poorly. Steve informed me that not being able to see her continue to grow and develop into the lovely young woman she is and see her children arriving and thriving would be his greatest regret and loss. Steve was very aware of what he would be missing, and this is an area which led to Steve being increasingly distressed as his death became closer.

41. The impact of Steve being ill for so long had major impact on his extended family as they didn't fully understand all the implications as he looked well until the last few years and were in denial of his diagnosis and minimised if he informed them about distressing and painful side effects. This led to difficult times for Steve as his parents were unable to support in a way in which he would have found beneficial, something Steve found difficult to accept. This led to Steve withdrawing from his extended family as he felt more isolated in their company that when he didn't see them.

42. As Steve's illness progressed and he was diagnosed with Hepatocellular Carcinoma his family tried to become more inclusive and accepting of the diagnosis but whilst Steve was realistic about his prognosis his parents struggled and had this optimism that a cure would be found. This led to again Steve feeling that he couldn't talk openly as they minimised and showed misplaced optimism. Steve was accepting that families should not have to go through these situations but was helpless to relieve anyone's distress including his own.

Impact on me

43. Physically I have kept well, I keep active and try to lead a healthy lifestyle. I experienced that looking after Steve when he became very poorly exhausting and demanded a lot of physical effort to keep things going as well as run the house, garden and work. I found that I needed to work part time in order to support Steve at attending the frequent medical appointments required and

reduce the demands on me. In 2014, I order to fit everything in and fully support Steve I took 3 months off work without pay in order to look after Steve as he needed constant care. I have experienced anxiety with fluctuating intensity and found that at times the physical symptoms of anxiety were overwhelming, very uncomfortable and included dry mouth, increased heartbeat and increased breathing rate, headache,

44. When Steve was diagnosed with Hepatitis C virus, I was fully aware that this was serious and would be a battle that I would need all my emotional strength to support him. When things deteriorated and Steve developed Hepatocellular carcinoma as a result of the hepatitis C virus I struggled greatly as I knew that this prognosis for this cancer was poor. Emotionally I portrayed that I was very strong to Steve and supported him at every point in order that he was free to make such difficult decisions about his care and treatment over an extensive period. Inside I have struggled greatly and found that watching my husband fade away in front of me absolutely and completely devastating. I struggle to find the words that can adequately describe how I have struggled emotionally during his illness, supporting him in death and since he died. Watching my husband draw his last gasping breaths is something that will remain with me forever and that in our daughters' memories and is something that neither of us should have witnessed in such an untimely way. Losing my husband in such an untimely way and needing to support our daughter has pulled on internal resources I didn't know I had. I have felt such sadness that I don't want to face the day and stay in bed and times of increased activity in attempts to stop thinking and distract from such sad overwhelming feelings.

45. My life has changed beyond recognition since Steve died and I find living alone a very lonely existence. I struggle to maintain the house, undertake DIY tasks, yet feel that I need to get things done to show people that I am coping. My reality and what I portray are two very different things and the disparity leads to me feeling again isolated, at times distressed but mostly lonely. This leads to feeling resentful that I am in this position and that I should not have been widowed at the age of 49 due to Steve being given contaminated blood during

an operation. This has impacted on most of my adult life and nearly all of our daughter's life.

46. My own extended family rallied round to begin, and I was supported however this level of support cannot be sustained and I feel very isolated, alone and feel even more isolated when I attend big family functions and feel that I have lost my main support. Steve offered me a solid base from which to explore but with this gone every excursion and event can be a trial.

47. There have been several years in which I was looking after Steve which prevented me having a full social life. I was busy working and looking after Steve that I didn't have the energy or want time away from home. I would become anxious when leaving Steve on his own as I wasn't sure that he would be ok and need medical help at any point as his side effects were so severe and unpredictable. Given that I was anxious if I left Steve on his own and him needing help and care I felt it was less stressful to stay at home with Steve. As a couple we therefore became isolated as friends, whilst were supportive, got on with their lives and we somehow got left behind due to our own priorities.

48. I feel that for the last 20 years Hepatitis C and subsequent cancer and Steve's untimely death has totally dominated my life. It has been an emotionally rollercoaster of the most phenomenal dimensions which no one should have to experience and to put the impact into words does not fully portray the intensity of negative feelings. This process is a struggle and I hope that I have gone some way to describe the impact experienced by Steve and myself.

49. Individually and as a family I am not aware of experiencing any stigma associated with a diagnosis of Hepatitis C.

50. Our daughter Mrs Christine Brindle, Steve's sisters Mrs Beverly Coleman and Miss Alison Hill will include their own descriptions of the impact on them and will include the impact on Steve's parents who both have died since Steve's death. All detailed in this section below.

Impact on Christine Emma Brindle. DOB GRO-C 1990. Steve's daughter.

At the age of 23 I witnessed my Dad trying desperately to breathe and struggling for breath as he passed away in the company of myself and my Mum. We had sat with Dad for around a week knowing that the end was near and that there was nothing we could do to help him only to make him feel as comfortable, loved, and as safe as possible.

Whilst dad was still able to talk about his thoughts and feelings given the desperate situation, he was able to articulate that his biggest fear was him not being around to look after us. He was fully aware that he would be missing out on seeing me and my husband change from a couple to a family and he would have loved his two granddaughters. Therefore, each big and small milestone which as a family we enjoy, is tainted by sadness and grief that Dad isn't here to share these family times.

It's hard to believe that my children won't ever meet their Grandad.

This trauma of losing my dad at such a young age is something I will never be able to recover from. I think about him and miss him every day and I am left wondering how much brighter life would be if my Dad had never contracted the Hepatitis C virus and was still with us.

From a young age I knew that Dad had the Hepatitis C virus but didn't fully comprehend the impact that would have on our lives. Mum and Dad sheltered me as much as they could until the day they found he had a cancerous tumour on his liver. After the tumour was found I could see for myself how serious the situation was and I witnessed Dad struggle when taking medications that were meant to help him. These side effects had a dramatic impact on his life and that was incredibly hard to watch.

This impacted on my mental health drastically and I experienced high levels of anxiety, distress and depression in addition to being inconsolably upset at times. I was unable to share how I felt with my parents as they were already going through such a traumatic time and I didn't want to add to this. I have suffered with depression and anxiety since then and need medication to be able to live a normal life.

As a teenager knowing my dad had the Hepatitis C virus, it was always in the back of my mind that he was poorly, and the future was unknown. Although I was able to attend college, university and get a job all with the valuable support from my Dad, I couldn't help but worry about what the future held for us as a family.

My Dad was the most special man and would do anything for me. He always helped and supported me in any situation despite how much pain or discomfort he was in. The fact that he was such an incredible Dad makes it even harder to have him missing from my life.

Losing a parent at such a young age would be hard for anyone to deal with however knowing that this could have been avoided makes the pain even more intense. Participation in this inquiry has been distressing however I want my voice to be heard and for the inquiry to be fully aware of how the infected blood has impacted on myself and my family.

Christine Brindle 28/09/22

Impact on Beverley Coleman (Nee Hill) - Steve's older sister.
Personal Impact Statement

On behalf of Bev (sister), Jack (nephew), Richard (brother in law), Brenda and Bob (parents, now both deceased).

Steve Hill was my big brother. He was taken from us in the cruellest way on 8 September 2014 at the age of 58 GRO-C before my 52nd birthday. It didn't seem right to have birthday tea that year.

Physical/Emotional

Steve's death devastated us all. We knew about the hepatitis and the cancer, but I still remember so clearly when he gathered us altogether to tell us that his life was now close to the end. It was many sleepless nights before it sunk in. Dad cried, mum was in denial. Normally as a close family we talked about issues, but dad didn't want to and all you'd get from mum was "when he gets better". Not being able to share concerns meant everything was bottled up. Mum said some very mean things to Ira meaning they had less contact, also meaning that as the closest child I got the responsibility of not only looking after my husband, son and myself, I was also responsible for mum and dad, a task which had previously been shared.

During the week leading to his death, in order to support Ira and Chrissy who did a superb job nursing him at home in accordance with his wishes, I spent many hours with them, helping where I could, sleeping over on occasion. Managing on very little sleep. Every day saw changes in Steve as his illness took him apart a piece at a time. During the last few days we had to stop mum going to visit as her comments of "when you get better" we're just so upsetting to everyone, especially Steve.

After mum and dad died, with Steve not being around and Alison (Steve's and my younger sister) living in Essex, I (with help from husband, Richard) ended up being the one it fell to to arrange the sale of their house, the clearance of 40 years of living there, sort out finances, chores which would have been shared if Steve was still around.

Emotional/Mental

Once Steve died, dad died inside. He gave the appearance of no longer having anything to live for, despite having a wife he'd been married to for 60 years, 2 daughters, 2 grandchildren and a great-grandchild. Overnight he became a shadow of how he had been. He could never accept that his son had died first. He'd keep saying "it should have been me". The most hurtful was that it never seemed good enough that myself and Ali, or even mum, were still there and needed him, it felt as though we were unworthy, rejected and nothing to him. Emotionally he was empty. Over the next few months things went downhill for him, he just lost the love of life. No longer going out, just sitting at home in front of the tv. He suddenly got very frail, just waiting to die. I didn't have time to grieve as it was straight into looking after mum and dad. Mum caused herself significant physical injury pulling him about, trying to get him motivated, up and dressed etc, to the extent I was so worried about both of them I called in social services to arrange some care. Dad died in December 2016, a broken man. Mum hadn't grieved properly, but when dad died it became more obvious that she had significant health issues that had been put to one side while she tried to look after dad. Myself and my husband had to do a lot of visiting and looking after them, often leaving our 13 year old son alone at home alone. Dad was always so active before, I strongly believe that if Steve had been alive dad wouldn't have given up and would have been around for a lot longer. Mum died in December 2018 having blanked it all out. I often wonder if the trauma of losing Steve brought on the dementia.

On GRO-C 2021, my son's 18th birthday, I reached the age Steve was when he died. I now feel I'm on borrowed time. I do things and think how Steve didn't get the opportunity. As each birthday comes and goes it brings it all back that Steve never got to 59 or 60. There but for the grace of God it could have been me not seeing my son growing up.

Even writing this I'm still grieving. 8 years and it still seems like yesterday.

Private, family and Social

We don't get to pub quiz. He's no longer the first to throw sweet wrappers about after Christmas dinner. It always feels like there's a person (or 3) now missing at the table.

We still make the same wisecracks Steve made "I'd like to say it's been nice to see you" but it's not the same anymore. Steve built our son a scale model Landrover. Despite having grown up and Jack not using it anymore, it was 5 years before we felt we could sell it on as it felt like betrayal of his memory.

Stigma

When someone asks about Steve and why he died I've always felt I've needed to clarify that he had liver cancer caused by hepatitis most likely caused by a contaminated blood transfusion. I don't want them thinking he was a drug addict or an alcoholic.

Impact on work

I was fortunate that my work allowed me time off to support Steve, Ira and Chrissy in the last week, but the work still had to be done when I got back.

Due to the stress caused by losing Steve, depression, not being able to sleep, the resulting effect on mum and dad, travelling back and forth to mum and dad, working, a teenage son, a husband (who I couldn't have managed without and also ended up helping for hours on end), not being able to concentrate or feeling that I could function properly, I ended up on the verge of a mental breakdown. I had to take 4 weeks off work in order to find some headspace. I was taking anti-depressants at some point but can't remember exactly when.

Financial

No financial impact.

Bev Coleman (nee Hill)
29/9/22

Impact on Alison Hill - Steve's younger sister.

Physical

Have never recovered from the numbness and disbelief that was caused by Steve's early death

Had to watch my previously healthy, full of life brother fade away

It was the first time I had really watched someone die and each visit showed me the end was getting nearer as I saw more and more deterioration

Lost my big brother, who I had always looked up to and tried to impress

In living away from him, I could not be with him on a regular basis and felt unable to help with the task of looking after him and supporting his closer family. I could also not be there when he eventually passed away due to having to travel back home for work commitments.

I was also not able to say a final goodbye by visiting the Chapel of Rest

So many memories of growing up with him, sharing our love of music and spending time at the pub with him. Private jokes that no-one else can share in.

Feel cheated of many years of memories

Mental

Had to come to terms with losing a brother too early. Where we were three, we are now two and it does not feel right.

Do not feel that I have gone through the normal stages of the grieving process due to the protection being given to mum and dad.

Has been a factor in why I have never really given any serious thought to getting married. It was always a possibility that my dad might not be around, but if that were the case, Steve would give me away. That is no longer possible.

One of the last times I spoke to my brother on the telephone, he was falling asleep as we were speaking and drifting away from me and I can't get that out of my head

I can't remove his mobile telephone number from my phone because of the feeling of losing him again

Made me think about why my dad could not keep going for me and my sister. Were we not a good enough reason to keep fighting?

I went on holiday just before he died, and I always feel guilty about this and the fact that while I was away, he was fighting to stay alive

Mental anguish caused while on holiday as updates from the family were not good and it was very stressful trying to work out if I could get an earlier flight home to be able to say my goodbyes

My final image of his face is him looking extremely thin and gaunt, with hollow eyes. I know it was my brother, but it didn't look like him.

Emotional

Only time I ever saw my dad cry, which destroyed me. I held him sobbing in my arms.

Mum could never talk about him without crying, so I felt like I was always having to be the brave one when I was around her

This led to me never really grieving properly as you should do, and I still feel very numb.

Always remembering us giving each other V signs on parting and getting told off by our mother, hurts to remember what would previously have been a happy and fun memory.

Steve told me that he had Hepatitis C before he showed any symptoms and when he was well and active. It was hard to believe at that point that it could lead to his death, and years followed where there was uncertainty and doubt about when and if the Hepatitis C would cause potentially life threatening liver damage. This was a time of constant worry and concern.

Private, family and social life

Our family was never the same again after he passed.

Losing his son was something that stopped my dad being the same dad. He was always sad and hopeless, and none of us could fill the void that Steve left

Steve died 2014, dad 2016, mum 2018

No more family Christmases, they just weren't the same anymore. The fun was no longer there and being there on Christmas morning was more of a duty than a pleasure.

Stigma

When explaining to people what he died off, I feel they are judging him for having Hepatitis C. This is how I feel, so I often find it easier just to tell people it was Cancer and not explain further. It seems very unfair that I should be in some way covering up the truth of what killed my brother, and he does not deserve that.

Impacts in work

Had to take time off work for bereavement and because I lived at a distance. This was OK and I was allowed some time off, but no-one did my job when I wasn't there and my time off had to be kept to a minimum and going back in was very stressful at an already difficult time.

Financial

No financial impact

Alison Hill 29/09/22.

Section 6. Treatment/care/support

51. The main difficulty was having to access regional specialist centers rather than local centers for assessment and treatment. Having to travel to Oxford and

Cambridge by car was taxing for Steve but having to travel to London by train when he was very poorly was inappropriate.

52. Steve was offered emotional support when he was very poorly in 2014 however, he didn't trust the NHS given his history he never felt it was safe so never accessed any psychological support.

53. I accessed local counselling after Steve died from my GP team.

Section 7. Financial Assistance

54. Steve worked full time throughout the time he was diagnosed solely with hepatitis C. He was able to take a day's annual leave in order to attend Oxford Hospital which reduced his overall annual leave entitlement. This led to less holiday time for us to spend as a family. Due to fatigue Steve was looking to reduce his hours to part time holiday cover only and this had been agreed with his employers. This however didn't happen as Steve was soon after diagnosed with Hepatocellular carcinoma and became too ill to work so was on sick leave until he retired from employment in 2011. After Steve retired, he did not contribute any money towards the household finances.

55. Steve was unable to draw on any pension plans at that age, so I had to continue to work to cover our usual expenses and keep the home running.

56. I worked full time until Steve was ill in a highly paid NHS role. I then had to drop down substantially to a job that gave more flexibility and was closer to home to be more accessible to Steve should he need any urgent help and support and paid less money. In addition, I also reduced my working hours and worked part time in order to take Steve to the ever-increasing amount of appointments.

57. As I was only 49 when Steve died, I was not entitled to a 'widows' pension' and was given a one off payment of £3000 to support with funeral arrangements. A widow's pension would have been substantially more and long term.

58. Steve was unable to work due to ill health and was therefore unable to contribute to the household finances. Our finances were worked out on Steve being able to add to the pot but after his death there was no state pension to come into the household when he reached the required age.

59. I was required to support Steve to get to appointments and to take him as very often he was too ill to drive. There were additional expenses in fuel costs as the regional hospitals he attended were not local to our home.

60. Also, when Steve was on the drug trial in London – whilst the trial paid for Steve's transport, I had to pay expensive rail fares in order to support his attendance or to visit him when he was an in-patient.

61. Steve was not aware of any funds or trusts available to him other than sickness pay from his employment then Personal Independence Payments (PIP) which he received for the last few months of his life.

62. I have not applied for or received any financial support from any trusts or funds as I wasn't aware that I could apply for any financial support.

Anonymity

63. I do not wish to remain anonymous, and I understand that this Statement will be published by the Inquiry. I do not want 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 ………………………….

Dated 31/10/22