Witness Name: Christina McLaughlin
Statement No: **WITN2778006**
Exhibits: **WITN2778007 - 43**

INFECTED BLOOD INQUIRY

THIRD WRITTEN STATEMENT OF CHRISTINA MCLAUGHLIN

I provide this third statement in response to a request under Rule 9 of the Inquiry Rules dated 23 June 2022. My previous statements are:

- Statement 1 **WITN2778001** dated 22 April 2019.
- Statement 2 **WITN2778005** dated 6 February 2020.

I, Christina McLaughlin, will say as follows: -

1. I was born on GRO-C 1971, and my address is known to the Inquiry. I intend to speak in this statement about my family members who have been infected with hepatitis C (HCV) and hepatitis B (HBV), via contaminated haemophilia blood products.

2. In addition, I will speak about my family's on-going issues that we currently have with the Belfast Trust, Hepatology Clinic, the Belfast Haemophilia Clinic and the Belfast Health and Social Care Board (HSCB). We are facing ongoing

barriers that have been escalated, I believe, due to my previous statements that my family and I have made to the Infected Blood Inquiry.

3. My brother Edward Conway (Eddie) who's date of birth is GRO-C 1958, is aware that I am making this statement, and I have been given permission by him to speak on his behalf. Eddie is capable of living alone, he eats a healthy diet and hasn't drunk alcohol in the last 15 years. He takes his medications and looks after himself. We don't make decisions for him, Eddie instructs us.

4. As I have stated in my previous statements, my cousin Michael Birtles died on 9 March 2018 (aged 59), of liver cancer who was a severe haemophiliac. He had HCV for 35 years. Michael's daughter Laura has provided a witness statement to the Inquiry (**WITN2880001**).

5. My younger brother Seamus Conway, was a severe haemophiliac and died with HCV (35 years untreated hepatitis). He died on 28 May 2018 (aged 45) from liver cancer.

6. In 2018, we were extremely shocked and frustrated at the speed of both their deaths, only 6 months from diagnosis to death, and we began asking questions of the Belfast Trust, Hepatology Clinic, Royal Victoria Hospital (RVH),
Haemophilia Clinic and HSCB. "How could this have happened undetected?"

Section 1. Introduction

7. In 2018, we started taking notice of the Infected Blood Inquiry, and we went to the Preliminary Hearings in London in September 2018. The horrendous stories we were hearing, although difficult to listen to; somewhat lifted a burden off us knowing we were not alone. John, Patricia and myself also gave oral evidence to the Inquiry in Belfast on the 23 May 2019.

8. I was represented by Collins Solicitors previously, and now I have decided to be unrepresented. My family are not currently members of the Hepatitis C Trust.

9. I am related to 4 HCV and HBV infected family members; 2 have passed and 2 are alive. At the time of Seamus and Michael's deaths, they were both still HCV positive, I found out that Seamus and Eddie were both infected with HCV in the 1980s. However they didn't get diagnosed until, I believe 1992/1993. The fella's did not know they were co-infected with HBV, and we only became aware after receiving their medical records. Even in 2018, Seamus never knew he had HBV.

10. I have been married to my husband Sid for the last 28 years, we have two children, a daughter Carla aged 23 years old and a son Luke aged 20 years. Luke has severe Haemophilia A, Carla is also a haemophiliac with Von Willebrand Disease. I have full permission to speak on behalf of my husband and children. I intend also to speak on behalf of my brother Seamus Charles Conway, and my cousin Michael Birtles, both deceased.

11. My family consists of the following siblings:

- Edward (**WITN2738001**),
- John (**WITN2964001**),
- Maria (**WITN2739001**),
- Patricia (**WITN2765001**),
- Paula (**WITN2927001**),
- Ann,
- Rosemary (Rosie) (**WITN2742001**),
- Christina (myself) (**WITN2778001; WITN2778005),**
- Seamus (**WITN2738001**) who was the baby of our family, and Marguerite who passed away at 8 months old.

12. In addition to having copies of Seamus and Eddies medical notes that we applied for ourselves in 2018. The Inquiry has given us further access to Eddie and Seamus's medical notes which were provided to us via the Egress electronic system. These relate to the following institutions:

- Western Health and Social Care Trust / Altnagelvin Area Hospital, Derry;
- Royal Victoria Hospital, Belfast;
- Belfast City Hospital, Belfast.

13. My sisters and I were all told we were not haemophilia carriers from a young age. At that time, I was told it would 'skip a generation'. However there was always a 50-50 chance of being a carrier as a mother, but 100% if you have a father with haemophilia. In 1992, Dr Maine sent a letter to my family offering testing. This came about as my sister Paula had a son that was identified as a haemophiliac.

14. Dr Maine wanted to do a family tree in relation to haemophilia and tested us for carrier status. Patricia, Rosemary and myself went up on the same day and had bloods taken. A few months later we went back to Dr Maine for the results. Dr Maine took Rosemary aside and told her, "Rosemary you are a carrier, Patricia and Christina you are not". Patricia asked "is there any chance the test could be wrong?" Dr Maine laughed and said "no it was a DNA test. So go away and have your family, it doesn't affect you." So I went away, got married, had two children, I had Carla in 1999, after two miscarriages and then my son Luke in 2002.

15. If I knew I was a haemophilia carrier, I would not have had children. I watched my brother Seamus suffer from this horrendous disease, and did not want it in my family.

16. Even back then there were opportunities to have children without the genetic abnormality, and with IVF I could have had more choices. But because my DNA testing was wrong I ended up with two children affected both with this bleeding disorder.

Section 2: Carla and Luke

Carla

17. Carla was born and had to have a blood transfusion immediately. At this point I still didn't know I was a haemophilia carrier, she was born without a third of her blood and my beautiful sparkling baby daughter had to get a blood transfusion the first day she was born. We didn't know why. The nurse was very concerned, and asked about the haemophilia in the family, they said "we cannot figure out what happened". I said "yes there is haemophilia in my family but I had a DNA test and I'm not a carrier." That was the end of the conversation.

18. Carla had a cyst when she was born, as she got older, we were told it could turn cancerous so it had to be removed. She had surgery at 1.5 years old and no one knew that she was a 'bleeder'. I went on to have Luke in GRO-C 2002, at Altnagelvin Hospital. Carla was at this time suffering from various childhood illnesses, and was very unwell so I left hospital with Luke, before he was 12 hours old. But had I known he was a haemophiliac, I would not have left the hospital.

19. When Luke was around 5 - 8 months he was rolling around, he would have bruises on his belly and knees. I don't know if I was desensitised, due to my brothers having huge bruises and that I myself, bruise easily. I had started giving Luke 'Nurofen' for his teething as he was suffering badly. But obviously I didn't know he was a severe haemophiliac, and anti-inflammatories are a 'no-no' for haemophiliacs. After weeks of running to the GP, we were told by

Dr Dempsey, RVH, "I am very sorry to say but Luke is a severe Haemophiliac (A), with level less than 1% as it runs in the family".

20. At that time we had told the GRO-D about our concerns over Carla's health with regards to bleeding, as she had to have a blood transfusion the day she was born. We asked that they test her for carrier status, but they refused saying, "she is only three years old and we don't test girls until they are 16 years old".

21. I think safety should trump an ethical reason, they stated that "maybe the child doesn't want to know if they are a haemophiliac and it's detrimental to their childhood to know she's a 'carrier'". I think it is more detrimental to take risks with her life/health and our local doctors needed to know this information.

22. In 2004, when Carla was 5 years old, she had to have her tonsils and adenoids removed in our local hospital Altnagelvin, because of repeated infections. We were extremely worried about her having surgery with a potential bleeding disorder; as Tonsillectomy is a very high risk surgery for bleeders. We asked the GRO-D to identify her as a carrier so she could get treatment if needed, but they again refused saying they would only check her Factor 8 levels.

23. At this time, I spoke to the World Federation of Haemophilia (hereafter 'WFH') and got some advice. They told me, "if your daughter is at risk, and you are concerned about the child, if they require surgery especially tonsillectomy then the child should be tested for carrier status, at the parents' request." But GRO-D again refused, saying that they had checked her Factor levels and they were normal.

24. However, we now know that infection, pregnancy, injuries and stress increase Factor 8 levels in the body, which gives a falsely high reading. I know that the clinic was also aware of this in 2004. This is because when Carla was 9 years

old, she broke both her kneecaps and the Altnagelvin Hospital admitted her. They were asking about her bleeding status. I said "she was a high risk". I called Dr GRO-D and said "they checked her Factor 8 level and she got a false reading of 78%". But he said "no, if you have an infection, pregnant or stressed you will get a false reading". She was still not identified as a carrier.

25. But Altnagelvin Hospital continued with the surgery, and to our horror, but not to our surprise she had a post-operation hemorrhage, her blood went septic and she almost died.

26. Carla had to have another blood transfusion. I often thought that GRO-D GRO-D would have stepped in, and saved our 5-year-old child. But knowing what I know now, I believe they would have let her die, rather than identify her as a bleeder. All she needed was Factor 8, not another blood transfusion.

27. In 2003, when Luke was identified as a haemophiliac. During this time, Carla had her blood taken as well by GRO-D. I believe that the GRO-D had tested Carla's genetic bleeding status without our permission. I think they refused to tell us about her haemophilia diagnosis to play down the mix up with my DNA test. They did not like that as we asked questions about my wrong test results as well (mentioned in Section 1).

Luke

28. Luke has always suffered from repeated bleeds into the groin, lower abdomen and lower back. This is one of his 'target bleeds'.

29. In 2012, we brought Luke to an appointment at the GRO-D He had a flare up of his groin bleed, causing him huge pain and leaving him unable to walk. At the clinic, we were met at the waiting area by a new physiotherapist GRO-D GRO-D who asked us to bring Luke into her room to be examined. I explained that he had a bleed and was in a lot of pain after travelling and that he would need to be examined by his Consultant, so we preferred to wait until then.

30. She replied stating "no I would need to examine him, I need to see him first they would expect me to see him". She persisted, and brought him into her room, made him remove his tracksuit bottoms and examine his hip area. He had the bleed at this point and Luke and I were becoming upset.

31. We then went to the Consultant Dr GRO-D but the physiotherapist joined us. They both proceeded to examine Luke again, as he was on the bed the physiotherapist kept repeatedly saying "there's nothing wrong, there is no bleed". I couldn't believe my ears. We weren't there to discuss if Luke had a bleed, we were there to discuss a more robust treatment plan to deal with the bleeds.

32. It was very clear that one side of his bum was very swollen and he was in great pain. Dr GRO-D seemed concerned enough to send him for an x-ray immediately. After the x-ray she didn't discuss a treatment plan, and at this point the physiotherapist was teaching Luke how to use crutches (with a bleed). I was furious.

33. A few days later the children's nurse, GRO-D phoned me at home to say they thought Luke had a septic hip and we needed to come back to GRO-D and bring a bag to stay overnight. This was the week before Christmas, Dr GRO-D put Luke into a bed, made him use a wheelchair for four days, and stopped administering Factor 8; this was strange to me as we had never stopped Factor 8 before.

34. I was then told to drive Luke to Musgrave Park Hospital for him to have an MRI scan, which took two hours. Luke was very stressed and sore during it. That evening we were told he could go home as the MRI scan was clear, so there wasn't a septic hip. I asked if Luke was now going to be given a Factor plan, for his groin bleed, and was told "no, just give his normal prophylaxis".

35. The next day I phoned GRO-D who was the adult haemophilia Consultant. He advised that we give Luke, Factor 8 morning and evening for a week and see if it settles, if not repeat like beforehand. We did this and it settled the bleed.

36. A week after this, GRO-D phoned and she was very excited and said “we know what is causing Luke’s issue, it was growing pains”. I was so frustrated, I asked “would a Factor 8 dose fix this issue?” She said “no, no, no, it wouldn’t”. I knew this, but I wanted to point out that when I increased Factor dosage over the week the bleeding had settled, so it could not and was not growing pains.

37. Unfortunately, I personally was very experienced in identifying bleeds, by that point I was in my forties and had seen haemophilia bleeds in every stage because of my family. I had dealt with bleeds in their rawest form, I watched my brother Seamus suffer horrendous haemophiliac bleeds at all levels with and without treatment. I had been raising Luke with a severe bleeding disorder, and Carla with severe bleeding issues, and experienced bleeding issues myself.

38. I told her how fed-up I was, as we didn’t seek treatment to question if Luke had a bleed or not, we were looking for support in treating it. I felt they were protecting their physiotherapist in her ill treatment of Luke, and if it was shown to be a bleed she would have done wrong. Regardless, it was poor treatment. GRO-D asked me to keep his advice secret. All of them are only always concerned about themselves, and to hell with their patients.

Great Ormond’s Street Hospital, London

39. A number of incidents happened, with the lack of communication, the lack of testing, having to fight to have Carla tested, and playing down Luke’s situation led us to leave the Northern Ireland clinic in 2012.

40. I told my GP in Derry, about the issues we were having in GRO-D and asked her if she would refer Carla and Luke to Great Ormond Street Hospital. She did. Carla and Luke moved to Great Ormond Street Hospital, Haemophilia Centre (GOSH) when Luke was 10 years old for 4 years. As we arrived in GOSH, as soon as we walked through the door, Dr Mathias immediately told Carla she was a carrier, "even before I test you I can absolutely say you are a carrier Carla, and not just a carrier but a systematic carrier with severe bleeding issues, and I will be putting you on treatment". She was 13 years old then.

41. Dr Mathias was amazing and she got Carla tested straight away. She was finally diagnosed as a severe Haemophilia A carrier with Von Willebrand disease by GOSH. Why was Great Ormond Street able to immediately test her; when GRO-D clinic never diagnosed her and did not treat her as a patient?

42. With Luke, GRO-D was telling us that it was a growing pains issue and not a 'SOAS' muscle bleed. GOSH confirmed it was a 'SOAS' muscle bleed. The difference in care we received in London was stark.

43. The majority of our time at GOSH was great, however we did feel that the GRO-D clinic was still very much involved. There is a system called Extra Contractual Referral (ECR), if there isn't sufficient treatment capacity for any health issue, in the country/area you live, you can be sent to another area for treatment, as Northern Ireland GRO-D this was an option.

44. We went twice a year to be seen in London, under GOSH. But through the ECR system, GRO-D were paying GOSH to treat us. We paid for the travel to London, and sometimes we got help with expenses.

45. However, even when we were in London, Dr GRO-D was telling London how to treat us and what dosages to give. I had a good relationship with Dr GRO-D at this time. So, when Dr Mathias suggested Luke could go back to GRO-D adult's haemophilia clinic GRO-D when he reached the age of 14 years old, we were happy with that plan. We thought at the time that we had a choice but we didn't realise that GRO-D had in fact made this decision.

46. We returned to treatment in GRO-D in 2016.

GRO-D

47. We weren't long back in the GRO-D clinic, until we started feeling that the clinic was simply a 'tick-box' clinic. We had taken Luke to be seen for various bleeds. But they only had one physiotherapist which we had poor experience with at the Children's Hospital. They had started a new system where the patient was assessed by the physio before seeing the consultant, and the physio reports to the Consultant before the patient's consultation.

48. As Luke didn't have a physiotherapist, I don't believe GRO-D physically examined him (i.e. put his hands on him), and every time we told Dr GRO-D that Luke was having bleeds he would brush it off saying "it's not a bleed, it's unlikely to be a bleed" or "no, we wouldn't expect it to be a bleed". This was so frustrating as we knew when Luke had bleeds, and Luke definitely knew when he had bleeds, and Luke was suffering.

49. If we listened to the hospital about Luke's bleeds, it would mean he had less than 6 in his lifetime. When he was actually having more than 6 bleeds a month, with no clinical support.

50. So, when I say it was becoming extremely frustrating going to GRO-D with Luke and GRO-D repeatedly saying that Luke was not bleeding, I really

mean it was frustrating. GRO-D also continued to repeat that he had a rugby player as a haemophilia patient and a professional footballer haemophilia patient and at Luke's last consultation he stated he had a semi-professional boxer as a haemophilia patient.

51. I was furious he was saying all of this in front of Luke who was a young teenage boy who adored football and sport but because of his haemophilia wasn't able to properly play it.

52. This doctor continued to show complete disregard for the serious nature of Luke's condition, this caused huge problems with us and Luke, however I don't believe any parents would let their child with haemophilia go into a boxing ring and have their face repeatedly punched. We certainly wouldn't, and it is extremely reckless for a haemophilia Consultant to think this acceptable.

53. I believe these were fabricated statements, all so he could play down haemophilia. He was constantly trying to portray, "they all lead normal lives" image which I suppose would explain prescribing reduced Factor VIII units, which saved money.

54. GRO-D only saw Luke once every six months, he ticked a few boxes and had no dealings in-between; that was left to the parents, to give up work, train in giving port-a-cath injections, train in intravenous injections, and living life on constant 'red alert', stressed about brain bleeding, and serious life-threatening bleeding from even the smallest injuries, and look out for serious life-threatening infections.

55. We couldn't even rely on support, when any or all of these things did happen. For instance, in 2017, we had planned to take Luke to America to attend 'Wrestlemania'. I was going to travel with Luke for a 5-day event. As we would each night be attending large packed arenas. I was nervous, especially since

they are very high up with very steep concrete steps, so I contacted 'Starlight Charity', and asked for their help in organising it.

56. They were extremely helpful and totally understanding. My family would be paying for the full trip. We were relieved because they would book and organise everything for Luke and I; including flights, hotels, and special assistance at all the venues.

57. After everything was ready to be booked, they sent me a form to fill out and Luke's haemophilia Consultant would have to sign it off. I spoke to GRO-D GRO-D personal assistant on the phone. She was lovely and very helpful, and said "leave it with me and I'll email it back to you". However, the next day she called me back to say Dr GRO-D had refused to sign the form, I was astounded and so was his personal assistant, she was a bit angry. She said she was "so sorry, and [she] didn't know why he wouldn't sign it".

58. I was so annoyed and explained we were paying for the whole trip. I also explained the charity was hardly involved, it was only for safety and peace of mind that experts had taken care of all the travel details. But she said "he would not change his mind", and she apologized again. The charity was also shocked and annoyed as Luke's haemophilia fitted all their criteria. This upset Luke, his understanding was his own personal Consultant had no care for his safety and was also undermining the life long, debilitating painful condition he has suffered, again it was as if GRO-D was playing down the seriousness of haemophilia. Nevertheless, we went to America and had a fabulous trip.

Dosage

59. In March 2018, Seamus and my cousin Michael were dying at the time. It was a terrible year. At this time, Luke had a serious eye bleed. I phoned, and a ward doctor, they said "wake him up, don't let him sleep, give him two extra doses of factor VIII and then bring him to your local hospital urgently". As it

turned out we only gave him one extra doses, because we didn't know at the time that Luke was only on half his correct factor dosage. They said "no need for scan", which was under the guidance of GRO-D It was such a serious bleed, we believed it would have needed a trip to the GRO-D clinic. But there was no follow up.

60. But in September 2018, we found out Luke was on half the Factor VIII dosage he should have been on. He was only on 2000 units, and he should for his weight have been on 4000 - 4500 units. I found out by phoning the Haemophilia Society in England and asked for some guidance, they asked "what's his Factor? What are his Kgs?" They asked the 'in house' Consultant and came back to me regarding his recommended dosage of 4000 units.

61. We went online and worked out Luke's factor VIII dosage. This calculator confirmed Luke should have been on 4000 - 4500 units, for his weight and height and not the low dosage of 2000 that GRO-D had him on. At this point, everyone I knew had been reduced by 50% of the dosage that they should have been on.

62. In Dr GRO-D oral evidence to the IBI, he said that they had access and used 'HaemTract' in Northern Ireland which as far as I'm aware is not true. The 'HaemTract' only came into use in March 2022.

63. Also in 2018, patients all over England, Scotland and Wales had access to an online dosage calculator. This is where patients or parents in conjunction with their clinic, could work out the correct dosage of Factor needed. The dosage calculator is not promoted here.

64. When we challenged GRO-D he said "you can use as much as you like, the budget is there". Why then did he have Luke and others on half the dosage? We were not allowed to adjust anything unless Luke had a bleed, and we were still under medical instruction by phoning the ward.

65. When he had a bleed, we would phone the ward. But they would say "why do you need it?" Constantly questioning if Luke had a bleed at all. We were always told by Dr Dempsey, "if it looks like and feels like a bleed then you treat it as a bleed", we liked this system as it put the child/ patient first, not the budget.

66. We (his parents) altered Luke's prophylaxis factor dose in line with his weight and height, and in accordance with the online calculator. Dr GRO-D said nothing.

67. A few weeks after the bleed, we had an appointment with Dr GRO-D he said "it was unusual" to have a bleed behind the eye, he said, "I don't think an eye bleed is usual for a bleeder". In his notes he blamed it on playing football. It was because he had a bad cold and blew his nose too hard due to the pressure. His eye had settled with factor VIII, but it had left a weakness. Our son could have gone blind, developed a brain bleed, or it could have been fatal.

68. The Haemophilia Society told me that Dr GRO-D asked for and was given an apology letter from them, for them advising me on the dosage for Luke, by Liz Carroll who was the Chief Executive of the Haemophilia Society in 2018.

69. Dr GRO-D was arguing that the Haemophilia Society was getting involved with medical opinion, it was all about him and never about the patient. We never got an apology or an explanation from him for deliberately giving our son the wrong dosage and putting him at risk.

Dublin

70. In 2018, considering everything that had happened in that year we decided that we had to remove Luke from GRO-D Northern Ireland. We started going through our GP, in the hope of moving to Dublin. We

thought he would be safer in Dublin with no connection to Dr GRO-D or his clinic; this was impossible.

71. It took 18 months as GRO-D refused to let us go. However we were told we could move through an ECR system and were told we were patients in Dublin with no connection to GRO-D

72. Luke and I had one appointment in Dublin, 19 February 2020, all letters arising out from that appointment were copied back to GRO-D Apparently, he had instructed Dublin to do my bloods and tell me they were normal, and sign me off. At this time, my own Factor level was 6% which is considered an extremely low (not normal); a moderate haemophiliac. Dublin did sign me off, on his instructions. The Dublin clinic were instructed to see Luke once and send him back to GRO-D Carla was never seen at all.

GRO-D

73. In 2020, we had to start all over again, as it was apparent Dublin wasn't going to work GRO-D wrote to us, saying that we were not welcome back in the GRO-D They were also blocking us from moving to another haemophilia clinic in the UK and Ireland.

74. At this point I was feeling very frustrated, I was calling GRO-D GRO-D the GRO-D who refused to reply to our calls, emails and requests for meetings. Every time I called, I was told she was passing my concerns on to GRO-D the Service Manager (who was like the gatekeeper). They had absolutely no consideration for the danger they were putting my children's health in, putting all of our health at risk, especially Luke.

75. After Dublin didn't work, I contacted the General Medical Council (GMC) asking for help with moving out of the GRO-D clinic. I explained everything to them from the beginning with Seamus, Michael, Eddie and Luke. But they told me it was not something they could help with, so I came off the phone

exhausted and distraught. However, I was made aware of the Patient Client Council (PCC), so I contacted them and was immediately informed that they could help with the transfer of Luke. With the greatest relief, I embarked on the transfer of care through the PCC.

76. I was assigned a lady called Alex McMeekin at the PCC. Alex worked extremely hard to find a way forward in moving Luke, Carla and myself completely to the Royal Free Hospital in London. After months of Alex being messed about by GRO-D, she had agreed a way forward.

77. The PCC helped us so much, and at this point I contacted the Royal Free to book an appointment but was told that they only had an ECR for Carla and Luke, not me. Alex was furious. Again, they had put us on an ECR meaning GRO-D was still the doctor, and GRO-D signed off on the agreement in the summer of 2021. I feel that GRO-D completely abused her position, to bully and intimidate us.

78. Alex and I set about contacting the GRO-D GRO-D I had emailed each member individually, hand-delivered a copy of the emails requesting a full transfer of care to London for Luke, Carla and myself, they ignored all my correspondence for 8 months.

79. The GRO-D contacted Carla and Luke stating they would be contacting adult protective services on their behalf, because we (their parents) were trying to move them to a new clinic. Absolutely shocking abuse of power. We saw even more intimidation, victimisation and scaremongering tactics. We wanted to have a family meeting to discuss Seamus's death and how we have been treated but we were refused. We were told that while we were speaking to the Infected Blood Inquiry; they would not correspond with us.

80. In 2021, Kate Burt had taken over as CEO from Liz Carroll at the Haemophilia Society. I contacted her in early 2021, desperate for some help in getting my family safe healthcare separate from the GRO-D Trust. Kate said she could help with the clinical move. We were hoping to move to Prof. Chowdary at the Royal Free London, with no ECR attached.

81. Eventually in November 2021, Alex got us a meeting with the GRO-D GRO-D Alex, myself, Sid, Carla and Luke attended in person, and Kate Burt, Haemophilia Society joined via 'Zoom'. It was agreed at the meeting that they would draw up a personalised contract which was explicitly not an ECR. Since this would take a bit of time it was also agreed that we would attend the Royal Free immediately so Luke could get the urgent support needed.

82. Unfortunately, a week after this meeting Alex left her job with the PCC, but had assured me we would continue on with the new contact via GRO-D GRO-D But after Alex left, GRO-D They are governed by the GRO-D Trust, so I don't believe they are able to be independent.

83. I have been trying to get a copy of the personalised contract since January 2022 from the GRO-D We were to attend the Royal Free again in July 2022, however when I phoned to book the travel arrangements, I was told that they had to speak with the referring Consultant who is GRO-D We have to seek permission for the visit, and yet again we are on an ECR, and still patients apparently of GRO-D We feel we are totally trapped in this system.

84. They had also said the only way we would be getting a move to another clinic is if we allow all our personal and private health information to be sent back to the GRO-D Clinic. Absolutely not, we will not be forced to agree to this, as it is a breach of patient confidentiality.

85. On 1 April 2021 GRO-D misled the inquiry during his oral evidence, when he was asked if a patient wished to leave his clinic to attend a different one somewhere else, and the question was posed "how does this work?" He stated "it was easy and you can just leave". This is not true. He knew at that time that he, (GRO-D GRO-D and the GRO-D were and are currently blocking and refusing Luke, Carla and myself to leave the GRO-D Clinic.

86. As I have explained in this statement, there are multiple serious issues, leading to why we wanted to leave this clinic. However, it's also simpler issues like not having access to technology, parents all over the UK can access and adjust their Factor usage via technology. The patients in Northern Ireland did not have access to Haemtrack until around March 2022, and as I'm aware to date, patients in Northern Ireland are still not encouraged to access the online dosage calculator (www.hog.org) which is available in England. Northern Irish patients are left in the dark ages when it comes to haemophilia care.

Luke's surgery

87. When Luke was a baby our health visitor found Luke had an undescended testicle and asked me to take him to the GP. The GP said it was sometimes moving into the abdomen, he said this can be common and it will settle into the correct position as Luke was still very young. So, I never gave it a second thought until two years ago.

88. In 2020, we found out that Luke needed surgery urgently for a growth, if not removed would become cancerous. It became paramount to have surgery under the care of a specialist haematology clinic/hospital. This meant, making the move to London was even more urgent, but this still fell on deaf ears with the GRO-D It felt like they were playing us like some kind of sick game. The GRO-D would only help us if they were still involved.

89. When the conversation came up, and we realised the testicle could still be in Luke's abdomen, (19 years later) we immediately rushed Luke to the GP as I was aware of this condition becoming cancerous if not urgently dealt with. As it unfolded Luke was sent to Urology in Altnagelvin Hospital and it was identified that he was still suffering from an undescended testicle, and after scans it was identified that it had died off, and needed to be surgically removed.

90. What makes this so disturbing is, all of Luke's life as a haemophiliac, he has suffered weekly painful bleeds into his groin, which became known as his target bleed. But in hindsight the bleeding was because of this testicle being situated in the groin/abdomen. Multiple opportunities were missed by GRO-D (Consultant Ms GRO-D) as they repeatedly called Luke's bleed in his hip, 'growing pains'.

91. Due to the urgent need for the surgery we continued ourselves, to pursue a surgery date through his Urologist in Altnagelvin. Luke eventually had his surgery on Friday 12 August 2022, it was done by Luke's Consultant Mr. Daniel Safar. So as far as his skills are concerned, Luke was in excellent hands, and he received excellent care from the staff on ward 3, Altnegalvin Hospital. While the operation worked and we had been desperate to have it removed, given the length of time it was in his body, it was far from ideal. As there was a high risk of bleeding and he should have been in a specialist hospital. Our local hospital Altnegalvin performed amazingly and took such fantastic care of Luke and we are very thankful to them.

92. After the surgery, Luke was extremely sore but extremely brave as he has been his whole life. Since he was in a surgical ward Luke couldn't have visitors (due to Covid), understandably, but he phoned us the next morning.

93. Luke was alone when the surgeon gave him some horrible news. I know he is 19 years and considered an adult, but to us he is still our child. On the phone,

Luke said that the surgery had gone well and the surgeon casually said “they have sent the tumor off to histology for testing”. Luke was shocked and worried due to it being referred to as a tumor, as he was only in to have an undescended testicle removed.

94. The doctor then continued to explain to Luke that “sometimes it can come back as benign, but it mostly comes back malignant, but the tumor had been removed now and if it tested as malignant that my plan would be to do one blast of chemotherapy in the area to make sure there were no cells left”.

95. The horror we felt when our wee son told us was unmeasurable. I was terrified, angry, furious, frustrated, devastated and I cannot explain what we are all going through at this time.

96. Again all because of the GRO-D GRO-D, GRO-D, GRO-D GRO-D GRO-D and GRO-D of the GRO-D and GRO-D GRO-D, abusing their position of power by covering for each other which has caused serious harm to our Luke. I am scared that these people would interfere with Luke’s testing, and make our local hospital tell him that the tumor is benign, even if it is malignant and tell him there is no need for treatment in order to cover their backs. This may seem like a conspiracy, but not to us, the GRO-D and Hepatology Clinic and these people are very aware that my brother Eddie is walking around with liver cancer. They have been blocking his opportunity for treatment, so similarly Luke would just be ‘collateral damage’. I believe that they knew Seamus had liver cancer for at least 4 years before he died and they didn’t tell him. I will discuss Eddie in **Section 3** and Seamus in **Section 4**.

97. We are now waiting for our son to find out if he has cancer, but again this could have been avoided multiple times if the GRO-D GRO-D Hospital had properly checked him. It is only in third world countries that boys go past the age of puberty with an undetected

undescended testicle, never mind to the age of 20 years old. Luke really had third world treatment at the GRO-D

Section 3: Eddie Conway

98. Eddie has some memory loss. The Belfast Haemophilia Clinic currently state he is suffering from Vascular Dementia, however we believe he is suffering from hepatic encephalopathy, a nervous system disorder brought on by severe liver disease causing a build-up of toxins from the liver, which is one of the negative symptoms of untreated Hepatitis C. Eddie gave a statement to this Inquiry (**WITN2738001**) 3-4 years ago, but a lot has happened since then.

99. During the year of 2018 my brother Seamus and cousin Michael died from contaminated blood liver cancer. Because of their deaths, we tried to get Eddie the liver scan referral from Gary Benson at his haemophilia clinic; but he wouldn't refer him. Benson continued to state that "his bloods were normal".

100. Despite repeated requests and Dr Gary Benson refusing to refer Eddie to the liver unit for nearly all of 2018, Eddie eventuality got an appointment with Dr GRO-D Hepatology RVH, on the morning of 28th November 2018. Eddie was given an ultrasound scan, then a consultation with Dr GRO-D, where D GRO-D told Eddie and myself that the ultrasound looked good and he was happy with it. We were pleased at this especially after Seamus and Michael's deaths, from liver cancer. I asked Dr GRO-D for a copy, but it was at this point the pleasantries ended and he became irritated, asking "why did we want it?" I explained "for the Infected blood Inquiry, we wanted to get a copy".

101. However, that exact afternoon, while Eddie was getting his bloods without me, Dr Neil McDougall sneaked in and performed a fibro-scan on Eddie. Following this I was sent for, and we were told by Dr McDougall, "Eddie you have advanced cirrhosis of the liver". But I cannot stress this enough, we both saw

Dr GRO-D in the morning, and were told "all good, and the liver was well", and he was sending Eddie home; this made no sense at all.

102. Yet Dr McDougall stated they have wonderful treatment, a new anti-viral medication where you take one tablet daily for 12 weeks and it rids the body of hepatitis. He called it a cure and that it stopped hepatitis attacking the liver further. I asked why Eddie wasn't offered treatment before, and why Seamus didn't get this magical treatment but he ignored me. I then pushed further and asked why none of our fellas Eddie, Seamus or Michael, got treatment or scans or referred to hepatology. He only responded saying "that's Dr Benson's department".

103. He spoke to Eddie, "Edward with those larger tumors that your brother (Seamus) had, the treatment of Euplusa wouldn't have helped (modern medications). But Eddie with these smaller ones it will". Eddie was just told there was nothing in his liver, in the space of a lunch time he was being told he had advanced cirrhosis of the liver, tumors, and cancer cells. He didn't have the capacity to have an appointment or be diagnosed without me present, and the doctors knew this.

104. On 5 December 2018, I emailed the Belfast Trust to complain about the shocking appointment Eddie and I experienced on 28 November 2018. I didn't send the email to the GP, but then out of the blue received a phone call from the GP and was told Dr McDougall can't ring me and that he (the GP) was ringing me on Dr McDougall's behalf. Eddie's GP went on to explain that he didn't tell Eddie or myself, on the 28 November 2018 that he had tumors, cancerous cells or cirrhosis. Their story changed, but he definitely did tell us. It was the most horrendous day, how could I forget.

105. Then during an appointment in May 2019, Dr McDougall couldn't deny it any longer that he told Eddie he had cirrhosis of the liver. But there was no mention of cancerous cells or tumors. So I asked him, "are you saying Eddie

doesn't have tumors in his liver, only cirrhosis?" He said, "he didn't have tumors in November, but there is a small 1 cm tumor there now."

106. He said the standard protocol is to see hepatitis infected patients every 6 months for scans. Dr McDougall was adamant "there were no tumors in Eddie's liver in November, and only a little half nodule/ tumor that wasn't there in November. But there is now." He said "yeah just a wee little one, we will send you to the local hospital for MRI scans, and get you 3 months plans."

107. Dr McDougall reported that Eddie's liver MRI showed one small lesion less than 1cm in size. He stated that they don't categorise anything below 1 cm as cancer. Instead they wait to see if it grows. However, when we got the reports he sent to Eddie's GP on the same scan, this report stated that Eddie had multiple lesions (i.e. tumors). One in the liver, and one in his pancreas was 18 mm in size, among others.

108. I understand not treating a lesion under 1cm, but in Eddie's case he had over 35 years of an untreated hepatitis infection, he had advanced cirrhosis and cancerous cells. They should have 'red flagged' him to Oncology, we had repeatedly requested Eddie to be referred to our local Oncology but still nothing has happened. I feel they are trying to let him die, just like Seamus.

109. From May 2019 through to January 2020, Eddie was sent to our local hospital Altnagelvin to have Liver MRI scans. Eddie found doing the scans extremely stressful and uncomfortable to go through. Eventually after the fourth scan, as he had not received any results, he refused to go back. He did not want to attend any further scans until he got a copy of the results. He has only got the interpretation of the scans according to Dr Neil McDougall but because of our experience we don't trust his interpretations. Despite repeated requests for the actual scans, they are missing from Eddie's Inquiry Egress medical notes.

110. In February 2019, Dr McDougall then put Eddie onto a new Direct-Acting Antiviral (DAA) hepatitis treatment for 12 weeks. Disturbingly, after he got the Hepatitis treatment, Dr McDougall contacted Eddie's GP, telling our GP to put Eddie on Statins. The GP put Eddie onto Statins as per instructions from Dr McDougall. But Eddie refused to take these, because on reading the accompanying leaflet, it warned not to be taken if you have liver cirrhosis and it is extremely dangerous if you have liver disease.

111. While he did receive a letter of apology from the GP for prescribing them, the GP stated that he had prescribed them because Eddie's liver function bloods were normal. Again this liver function blood test that is being reported as normal by both the haemophilia clinic and hepatology clinic is clearly misleading, but the GP acted in good faith.

112. Statins would have killed any liver function remaining and as a consequence would have killed Eddie. Eddie would be dead, and Dr McDougall would have probably said "oh no, it's not our fault (liver clinic) it was the GP".

113. These liver function blood tests that Gary Benson reports at his clinics and state to patients that everything can be seen in the bloods, gives patients a false confidence that their livers are healthy and safe. In my view it is either, clearly not fit for purpose, or deliberately being falsified, in order to 'gaslight' these hepatitis infected patients to a certain death from liver cancer. This has been the fate of Seamus and Michael to date and had we not stepped in would most certainly have been the fate for Eddie.

GMC

114. By the end of 2019, we were still trying to get out of Belfast Haemophilia Clinic, and were still being blocked by GRO-D, GRO-D, and Gary Benson to move from the Belfast clinic. I contacted the GMC and asked them to help us to transfer our care to London. They explained they couldn't help with this as it was not in their remit; however they then called me back

two weeks later to explain that they were very concerned about what I had told them about Seamus, Michael, Eddie and ourselves.

115. They called only as a courtesy to let me know they had decided to start an investigation into the doctors at the Belfast Trust. I was very happy to hear this as we couldn't get any answers about our brothers' death. They said they would be back in contact with me throughout, as it "was in the public interest". However, it was a bogus investigation and they never let me forward all of the information that I told them I had. They emailed to inform me that they had closed their investigation saying the doctors had done nothing wrong.

116. This was very hard, as this is yet another agency that pretended that they were interested in the welfare and care of patients in Northern Ireland.

117. A few months later when Eddie was thrown out of the only liver unit in Northern Ireland, it was stated this was because of the GMC's investigation (**WITN2778025**; **WITN2778024**). As part of the conversations I had with the GMC, I raised questions about the deaths of Seamus and Michael, and the lack of surveillance by the hepatology and haemophilia clinics.

118. The Royal Victoria Hospital's liver unit has failed to look after Eddie, he has refused to attend our local hospital as they don't have a liver clinic. Eddie is currently looking to move to a London clinic. But like ourselves, we are finding this an impossible task.

Section 4: Seamus Conway

119. In 2008 we met Dr Gary Benson, the new Clinical Director of the Haemophilia Centre in NI, Belfast City Hospital. After a few years as consultant he brought the haemophilia clinic to Derry, so patients attended our local hospital Altnegalvin, every six months or so. He was very good and we were excited. He was saying all the right things to us, and made us feel really good and

hopeful. He was only treating haemophiliacs, but I think he may now also deal with Oncology.

120. In 2008 my mother died. My mum was in charge of Seamus's care, so six weeks after she died, I took Seamus for a scan to Belfast City Hospital. On 21

121. October 2008, Gary Benson met us. He thanked me. He made a comment, "this boy fails to turn up". I couldn't understand where that was coming from. 121. If he had potentially missed one appointment it was understandable as his mother had just died. I believe he was setting the stage, early on, to portray Seamus as a serial non-attender. Gary Benson was the only Consultant available.

122. Benson took over from Dr GRO-D. She was there from 2003-2008. At one point there was no Haemophiliac Consultant for adults in Northern Ireland. We think the Belfast clinic knew that Seamus was ill as far back as 2008 or 2009, when Dr GRO-D did the handover to Dr Benson.

123. In his notes, she stated that to look after Seamus, as they were concerned about his Liver. There are medical notes that allude that in 1980, he had Hepatitis C (**WITN2778036**; blue pen is my own handwriting). He was only 6 years old.

124. **WITN2778039** shows any bloods in his notes up until now, up until and including 1979 which didn't show asterisks (an asterisk is a sign of abnormalities). But all bloods in his notes from 1980 were riddled with asterisks and readings well outside normal range. This would indicate that what medical professionals were stating was incorrect and the year Seamus was infected with hepatitis was 1980. So, when he died aged 45 he had been left with untreated hepatitis C and B infection for 39 years.

125. In his medical notes from 3 November 1995 from the Royal Victoria Hospital, Dr Butler took Seamus's blood at the children's unit (**WITN2778038**; the

handwriting is my own). Seamus again had abnormalities and numerous asterisks beside his AST and ALT results. These are a sign of liver disease. We were always told that the bloods would show everything, however when Seamus was consistently showing signs of liver disease in his bloods, nothing was done about it.

126. In his hospital notes (**WITN2778037**) from a 2014 admission to hospital it states 'Hep C (1980)'. This is shocking that they actively knew since he was 6 years old that he was infected. It seemed to be common knowledge that Seamus had been infected with hepatitis in 1980. My parents were definitely not told at that time, it was not until years later.

127. **WITN2778007** shows that Seamus had Hepatitis C in 2008, and in 2009 it notes that he recently had attended the Belfast City Hospital, where there were no reports of evidence of cirrhosis, but there are notes of 'Hep C' at the bottom of his medical notes. We think his doctor (Dr Maine) at the time found out he had Hepatitis C in 1980 but did not inform Seamus or our parents until late 1980s or early 1990s.

128. Seamus's notes in 2009, shows he had rectal (PR) bleeding in the back passage. Factor VIII would apparently 'dry it up', but doctors should have investigated this further, as it is a sign of gastric cancer. He would have a PR bleed, taking Factor VIII would have camouflaged it and dry it up and sort the bleed out. All these strong cancer indicators were ignored, and should have been a huge red flag for gastric cancer.

129. My cousin, Michael, was also bleeding in his back passage. But again, nothing was done, they told Michael he had colitis but never sent him to a specialist nor did they put him on the required specialist diet needed to alleviate the symptoms of colitis. I don't believe Michael ever had colitis, as PR bleeding is a clear indication of liver cancer.

130. On 16 March 2011, it looked like Seamus had a brain bleed and nobody was told about it. Seamus never knew this, it noted that in 2012 Dr Benson mentioned 'to check his bloods specifically regarding this'. **WITN2778019** (the handwriting is my own) shows the high levels of AST Serum Level and ALT/ SGPT Serum Level. My understanding is that these were signs of cirrhosis.

'Alcoholic Liver Disease'

131. Alcoholic Liver Disease (ALD) was being noted everywhere between doctors about Seamus's (**WITN2778013;** handwriting is my own). However Gary Benson never put ALD on any of Seamus's medical notes.

132. In 2016, their comments changed from ALD to Chronic Liver Impairment and Chronic Hepatitis C. Again, if Seamus had ALD, Chronic liver disease, this should have been coming up in the bloods, and if it was coming up in the bloods, why was he not told or treated appropriately?

133. In 2017, in a Dr McRory letter, Seamus is said to have 'HCC viral cirrhosis' and this was the first time that I can see in the notes that ALD wasn't the reason for the Liver disease, but it was instead his viral Hepatitis infection.

134. Dr McDougall had added him to the list in 2017, for 'surveillance'. But this was after his GP at Foyleside family practice, sent him for an emergency scan at hospital. They are trying to show that Dr Benson referred him to be looked at, but this is absolutely not true, as Gary Benson has said Seamus didn't turn up for the 3 appointments a full year and a half before his terminal diagnoses, so I wonder when did he refer Seamus, and if so what prompted this referral?

135. Dr Benson never told Seamus (his patient) that he thought he had ALD, the fact that Seamus had no idea he had any liver disease is just disgusting. Furthermore, how did Gary Benson know Seamus had liver disease when Seamus never had a liver scan? The only way he could have known is through the liver function blood test taken at his clinic that he always reported

as being normal? I believe that Gary Benson was setting the stage that any liver disease that Seamus would develop by his own doing and not because of the HCV infected blood, which was injected into him as a 6 year old child by his predecessors.

136. To qualify for the first stage of the NHS payment scheme Seamus needed to demonstrate he was chronically infected with hepatitis C and identified as a victim of infected blood. This is the eligibility criteria that qualified Seamus for the scheme and he received the 1st stage payment in the early 1990s. Then some years after this, Seamus was made aware of a 2nd stage payment; this is the payment he very accurately named the 'dead man's payment'.

137. The eligibility criteria that qualifies a person for the 2nd stage payment is: Cirrhosis, Primary liver cancer, B-cell non-Hodgkin's lymphoma or Type 2 or 3 cryoglobulinema accompanied by membranproliferative glomerulonephritis (MPGN).

138. Seamus's medical notes show that his liver function bloods showed signs of liver cirrhosis and liver cancer for years. Seamus received the second stage payment in February 2018, at the same time, he found out about his devastating death sentence. He was told that he had terminal liver cancer and only 3-6 months left to live.

139. Dr Gary Benson as the medical practitioner had to complete 'Section 1 to 8' of the application form and provide supporting evidence from his medical records. I believe this is the reason why Gary Benson withheld diagnosis of cirrhosis from Seamus's notes, and made sure that any other doctor dealing with Seamus, put ALD. This is because Seamus then would not qualify for the payment, if Seamus was seen to have liver disease from another means like alcohol, and not the infected blood.

140. Dr GRO-D was the only one to accurately acknowledge Seamus's historic cirrhosis and liver disease was as a result of his untreated hepatitis infection left to linger in his body and allowed to progress into terminal liver cancer; albeit he only told the truth after Seamus was told he was going to die. 141. A lot of haemophilia patients believe there is no connection to the treating Consultant and the infected blood payment and schemes (Skipton fund, EIBSS, and whomever is the Northern Ireland equivalent). So in saying that, I would like to draw the IBI's attention to Gary Benson's, oral evidence made on the 1 April 2021. He states, "I sat in front of a mother who just wanted her son, and all I could do was hand her a cheque" (**INQY1000117**). Gary Benson is referring to the 2nd stage payment. This gives Gary Benson a lot of power over his patients, a very dangerous combination, judge, jury and executioner. I believe he performed these duties well.

141. In Seamus's Altnagelvin notes there were concerns by local doctors about ALD and questioning the possibility of Gastric Cancer from 2014 - 2016. Dr Benson controlled everything to do with access to treatment. Dr Benson said Seamus cannot be managed outside of Belfast due to his complex needs. But this was his way of keeping control over Seamus and stopping any other clinician finding what he knew and I believe was trying to hide, advancing liver cancer.

<u>Missing Appointments</u>

142. Dr Gary Benson says Seamus didn't turn up for clinic appointments, he states Seamus didn't attend at all the year of 2003, however in his medical notes it shows he attended appointments on 04/02/03 and 30/01/03 (**WITN2778008**).

143. In 2004 he states Seamus didn't attend 7 appointments. But why was he expected or needed to attend 7 appointments in a year? When they usually only offer 2 appointments per year? Nevertheless, Seamus did end up going to 2 appointments in 2004 (**WITN2778008**; 02/02/04, 11/05/04).

144. Dr Benson was sent a letter to Mr Mullally regarding a clinical appointment on 16th June 2008 (**WITN2778011**; annotations are mine). However, in Dr Benson's statement (**WITN3082001**), it says that Seamus did not attend on 16th June 2008, even though Dr Benson wrote a letter demonstrating that he did. For instance, if you look at 16/06/2008 (**WITN2778011)**, it states DNA (we believe this means 'did not attend'). Therefore, there could be no trust of what Dr Benson has said in his statement.

145. He definitely did not miss these appointments. I refute Gary Benson notes. The notes state for example, on 18th January 2008 (**WITN2778008)** it reads DNA for Seamus. However, appointments Seamus did attend were 21/11/08, 02/05/08, 01/07/08, 16/06/08, 15/08/08, 07/08/09, and 02/04/09. But I note that the 06/01/09 date is not included on Gary Benson's list.

146. In 2011, **(WITN2778034; WITN2778033)** Gary Benson said Seamus did not attend the clinic on 04/10/11 and wrote to Seamus's GP, Dr J.C. Stone, criticising that he failed to attend his appointment. But when I looked at this letter (**WITN2778034)** I noticed the Hospital number looked different, when I checked it against Seamus's Altnegalvin hospital number they were different. I then noticed at the bottom of this letter a different man's name, H+C no and BCH number.

147. This was the paper copy of Seamus's medical records we had, so I thought I would check for the same letter on the Infected Blood Inquiry's, Egress copy, the letter was there, however someone redacted the Altnagelvin hospital number with a black marker, and handwritten Seamus's Altnagelvin number below.

148. So not only has Dr Gary Benson manipulated another patient's hospital letter to make it look like it belonged to Seamus, he has in doing this, breached this patient's confidentiality.

149. In Seamus's medical notes titled 'Patient Summary' (**WITN2778016** - the handwritten notes are mine), which is dated 16th March 2011, there are numerous references to asterisks on his results. An asterisk demonstrates abnormalities outside of a normal range. From 2011 - 2014 there were signs of abnormalities. So, if it was known then, how was this missed?

150. For example, in a letter from Dr Benson regarding a clinic appointment on 17 February 2011, Benson notes that Seamus had 'severe Haemophilia A complicated Hepatitis C'. Any of Seamus's clinical bloods that we have copies of and all have asterisks against them from as far back as 1980. There are abnormalities shown but nothing was ever done or said, Dr Julia Anderson, on leaving 2006/07 on hand over, said 'Seamus would need his liver kept an eye on due to its condition'.

151. There are numerous references to Seamus missing his appointments **WITN2778015**; **WITN2778008; WITN2778009** (handwriting is my own notes). All the blood tests were done in the clinic. If you look at **WITN3082008** **(**Patient attendance summary for Seamus) at entry number 9, on the 12th February 2016 it shows that he apparently didn't attend for over a year? As it shows 'DNA' (presumably 'Did Not Attend'), and only attended in August 2016 for that whole year.

152. This does not explain how they then got his bloods. He is shown that he did not attend from 21st November 2014 - 12th August 2016. It also shows CND (presumably means 'cannot attend'). There are no copies of the appointment letters sent to Seamus to attend these clinics or the reminders and calls, supposedly sent to him.

153. In January 2016, Dr Benson had conversations and wrote notes to Seamus's GP (cc'ing Dr McDougall), saying "again he hasn't turned up and I wanted to speak to him about the conditions of his liver. Hopefully if he turns up next time, I will send him for scans to Dr McDougall." His appointment was in April

2016, he pre-empted and dated the letter for July, and I think he was back tracking on his paperwork. Less than 6 months later, when Seamus did attend his appointment nothing was said by Gary Benson, about sending him for a liver scan or treatment etc. My heart breaks knowing that my lovely brother was terminally ill and obviously suffering and the people he trusted were taking care of him, were in fact working on escalating his death.

154. From Dr Benson's exhibit **(WITN2778008; WITN2778009;** handwriting is my own), it shows 'DNA' regarding not turning up, and some were regarding Dr Judith Anderson, but this was for dentistry not his clinic. I don't know what this has got to do with HCV and Dr Benson's notes. Seamus was signed off from the dental hospital. He has not had access to dentistry. A lot of people were like this. I don't know why Dr Benson was trying to use this against my brother.

Cancer

155. In 2014, Seamus broke two bones in his leg, he was transferred to the Belfast Royal Victoria Hospital, as an inpatient, he was on a ward for 3 weeks, which is managed by Belfast City Hospital Haemophilia Centre, Gary Benson. I know that Dr Benson attended rounds daily as the haematologist, and saw Seamus. This would have been an ideal opportunity to scan Seamus's liver.

156. Yet again deliberately missing any and all opportunity to identify and treat his liver cancer, which was liver cancer he developed from decades of untreated hepatitis, even when our local doctors had tried to draw his attention to their concerns of gastric cancer.

157. In 2014, there were many X-rays on his hips and there was no explanation as to why, I think this was related to bone cancer. This still wasn't properly investigated and should have been sent to see a bone specialist, as a bone lesion was first seen on an X-ray of Seamus's in as far back as 2010, a destructive Iliac lesion was found, it was still there when he was dying in 2018. Gary Benson was always saying he can't be managed outside of the

haemophilia clinic and stopping any doctor looking into Seamus. But nothing was done for him. Again, letting him die, and stopping any other clinician interfering.

158. **WITN2778012** (handwriting is my own) is a Radiology Report dated 30 April 2018 which refers back to a previous imaging abdominal x-ray done on 23 October 2010, which reads, 'a destructive lesion seen in the right iliac bone'. He was dying and they were talking about a scan in 2010. They found the same thing that they found 8 years before. Why were we not told about this in 2010? Why was this all coming out only when he was dying?

159. An undated medical note (**WITN2778014)** says 'severe Haemophilia A, known to Dr Benson', 'early ALD – as per Dr Benson's knowledge'. It even said 'Hepatitis C' and Seamus didn't know how serious Hepatitis C know or even that he had active Hepatitis C, he was not concerned as he was confident that he was being taken care of, as his bloods were being monitored at his haemophilia clinic, little did he know he was never going to be told about cancer, terminal cancer or any cancer. I believe they hoped he would just die.

160. **WITN2778015** medical notes from Belfast to Altnagelvin Hospital (30 April 2018) reads, "I note from the ECR that the patient has cirrhosis secondary to HCV and alcohol, portal hypertension, multiple liver lesions, portal vein thrombosis. This information was not provided in the referral form." This demonstrates that even when he was referred to a doctor in Altnagelvin Hospital; Belfast City Hospital wasn't giving vital medical information about Seamus's health to other medical professionals in the same country. Altnagelvin Hospital states that "information was not provided in the referral form." I do not feel this appropriate care.

161. I'm not sure of the dates, but sometime in the 1990s Eddie and Seamus were put on the Interferon treatment, for their hepatitis C infections. But both Seamus and Eddie didn't finish the treatment of Interferon & Ribavirin, due to

the severity of the side effects. Only after pressure from us, Eddies received modern treatment for hepatitis in 2019. Seamus never received it nor was he ever offered direct-acting antivirals (DAA), even though this amazing treatment was available in Belfast from 2013. The DAA would have prolonged Michael and Seamus's lives.

162. I don't believe that any hepatitis C infected patients, (through blood products) in Northern Ireland have not to date been given the new DAA treatment. I don't believe they are being given 6 monthly scans. I believe the hepatitis infected haemophilia patients are still being monitored through the liver function blood test exclusively, and falsely being told their LFTs are normal and therefore not being given appropriate surveillance.

163. Dr Benson's response (**WITN3082015**, Question 21, para 66) said all his HCV patients were cleared of the infection. "Further to their availability, all patients either treatment naïve, or refractory, have been reviewed, assessed and offered treatment- all but one patient has achieved a sustained virus remission".

164. This was not the case for my family. I don't believe any patient in Northern Ireland has cleared the virus, due to the fact hardly anyone is offered the new DAA treatment. I believe this man would have no trouble misleading the inquiry if it were to his benefit.

Psychological Support

165. Our dad died in 2013, Seamus tried to commit suicide and he went to the bridge, over the River Foyle in Derry (a regular suicide location). We all rallied around him. My dad was one of his biggest supporters. He opened up to Dr Benson at an appointment (N.B. Gary Benson said Seamus didn't attend any appointments in 2013, another lie).

166. Dr Benson referred Seamus for counselling, so about 6 weeks after this I went to a counsellor with Seamus. While we were chatting the counsellor kept asking him "how many drinks would you have weekly?" Seamus said "I haven't been out much so I haven't really been drinking." The guy said "oh that's very good, and again asked, so how many units would you normally drink in a week?" It was becoming a bit frustrating as he didn't want to talk about Seamus's suicidal tendency.

167. I then asked "what kind of counsellor are you?" He said "an AA counsellor", at this I explained, Seamus isn't an alcoholic. He is grieving, and feeling suicidal". That was the end of the counselling. He would ask for help and he still wouldn't get it. Again, Gary Benson didn't miss an opportunity to build a false picture of who Seamus was.

Section 5: Other Issues

Medical Records (via IBI Egress)

168. Eddie himself has about 400 pages of notes from Belfast City Hospital haemophilia unit, these are missing from the Inquiry's Egress copies. Seamus and Eddie were both treated at Belfast City Hospital Haemophilia Centre;

169. Seamus only received Altnagelvin Hospital notes Seamus didn't have many medical Belfast City hospital notes at all.

170. On another medical note from 2018 (**WITN2778021**), these are from Egress, they again show abnormalities in his bloods. I did not have access to these notes before the Inquiry supplied them to me. All these abnormalities should have been treated and he should have been looked after.

171. Belfast City Hospital only gave two charts for Eddie (Chart 2 & 3) these charts state 2 of three and 3 of 3, therefore we are missing Chart 1 of 3. Egress had none of these charts. Again, this shows how Seamus should also have notes

for Belfast City Hospital, Haemophilia Clinic, instead he only had been given Altnagelvin Hospital notes. This means we are likely to be missing 100s of medical notes for Seamus and at least 1 Chart for Eddie from Belfast City Hospital.

172. Within the Egress material, there are missing screenshots and images. There are letters that have been referenced in medical notes but are not included and should have been. There are also areas that say Seamus 'DNA' appointments but other documents demonstrating that he did actually attend.

173. So more medical records are needed to demonstrate his absence. I found there was a lot of stuff missing.

174. At every clinic, we saw Gary Benson make handwritten notes during the consultation. Why have none of these been supplied to us or the Inquiry Egress notes? Usually the doctor keeps the notes and uploads the information onto the ECR for the GP. Where are both of these notes?

175. **WITN2778007** relates to Altnagelvin Hospital, on 21 October 2008, Dr Benson would write clinical notes in the consultation, and then he would have had them typed up and send them with the ECR to the GP. This was the normal procedure, on this document and occasion there is an example, Dr Benson wrote to Dr Stone re Seamus, Cityview Medical Waterside Health Centre (GP). This is the only evidence we have of his notes. We have been through our records and the Inquiries records (Egress notes). This is the only one found, which was found by both our medical records and the Inquiry had. So for 10 years until he died, there were no notes or anything else, there were no typed notes? I would expect to see the handwritten notes, and there should be a lot more notes.

176. Seamus's first medical file didn't have the X-ray stuff (**WITN2778012**). I cannot find anything for Seamus regarding scans. From my review, the majority of his

medical files are missing. I have reviewed and there are a lot more X-rays that do not have linked medical notes.

177. We had asked the Belfast Trust on 20th November 2018 for medical notes, for Seamus and Eddie. This took months to be given to us. The Haemophilia clinic was in Belfast City Hospital, and they would then be seen 6 monthly in Altnagelvin Hospital, Derry. When Seamus was dying we went to Altnagelvin; you went to your local hospital. There are notes from Altnagelvin that are missing from Belfast, some are also changed. For instance, in Benson's statement, he states, he had sent bloods. I know that doctors hand write notes, and so many notes were missing.

Psychological Support

178. 2 days before Dr Benson gave oral evidence at the Inquiry (1 April 2021), Gary Benson decided to send out a leaflet to patients offering psychological care, and a personal letter to all his patients. Strangely, even my cousin in

179. Australia, who had never been Dr Benson's patient, got the letter. During his evidence he said "it is entirely confidential". Luke, my daughter Carla and I were excluded and didn't receive this letter.

180. At this time we were trying to leave the clinic. My brother Eddie did receive a leaflet, and so did all of my friends and family members who were patients. It said something along the lines "for the ongoing Inquiry, I will be giving evidence that will be bringing up unsettling thoughts, and you can come to the clinic." But apparently the clinic was already offering psychological support through funding.

181. Nobody at the clinic knew about this psychological support, it was only if you actually asked for support. That day I called Belfast Haemophilia Centre- and asked about psychological support and I asked if it was confidential, or confidential within the medical team? She affirmed the latter, that counsellor

sessions would later be discussed with the clinic team, Gary Benson, the nurse, the physio, the OT, the phlebotomist. For me, this was completely unacceptable and in no way confidential.

182. Dr GRO-D Head of Psychological Services, assured me she would arrange psychological support locally for our family and outside of Belfast Trust she just had to talk to her GRO-D (the gatekeeper). GRO-D GRO-D is the Service Manager for Haemophilia care, Psychological Services and Cancer Services.

183. As our family had just experienced two family deaths from contaminated blood, we do not wish the doctors we believe responsible for their deaths to be privileged to the information from our potential counselling.

184. On 1 April 2021, half way through Dr Benson's evidence, I received an email from GRO-D saying 'that the only psychological support we could have, would be through Belfast clinic and if we don't like more or less tough, also it's not confidential and no other areas of support are going to be made available to us'. I don't know if this was on purpose or not, re the timing of the email during his evidence.

Dosage

185. All of Luke's childhood, there was an established system for testing. Dr Dempsey had always requested it was possible to abstain from Factor treatment for 48 hours before an appointment if there was no bleeding, this was in order to test for inhibitors and to get an accurate reading of peaks and troughs.

186. In September 2018, Eddie was going to clinic and said, "oh I better take my Factor, I always take it". I said "do they not tell you to abstain if you don't have a bleed?" Factor levels are taken to identify their peak and troughs, but the

result would calculate high Factor levels, if they had taken Factor 8 before an appointment.

187. I was aware that all the men had their Factor units reduced by half, like Luke, Seamus and Eddie in particular were reduced from 3000 units to 1500 units Factor. Eddie said he was never on 3000ui of factor he believes the highest regular dosage was only ever on was 2000ui until he was reduced to 1500ui three days a week, by Gary Benson stating he is not as active and doesn't need as much factor, this is unbelievable Eddie should be on at least 4000ui every other day.

188. Before Seamus died he was in Altnagelvin, no one from the Belfast Haemophilia clinic in particular Gary Benson would return his calls and he needed to discuss arrangements for his daughter after he died, due to her being a haemophilia carer. But he ignored Seamus, I then emailed him as Seamus was suffering terribly and we needed help, he replied to me stating he would contact the ward but it all felt very cloak and dagger. I couldn't understand the lack of direct support as Seamus was dying and had been his patient for the best part of ten years.

189. Our local doctors and hospice were brilliant but they had no knowledge about haemophilia bleeds. At his end of his life, Seamus was riddled with painful bleeds up and down his body. Helen Manson, haemophilia nurse phoned the Altnagelvin Ward, not Seamus, and requested they remove Seamus's Personal supply of Factor from him, and only inject 500 IU per day. It has always been customary when in hospital, that haemophiliacs bring and administer their own factor 8, home treatment supply.

190. This was unbelievable as 500 IU a day wouldn't even be given to a small baby, never mind a grown adult man who was dying. For Seamus's height and weight, he should have been on about 3500 IU - 4000IU every second day at least. This would be without active bleeds, Seamus was suffering bleeding

daily at this time, and would have required double daily dosage. However he too was reduced by Gary Benson, a few years before, to just 1500ui three days per week so Seamus wasn't anywhere close to the appropriate factor 8 coverage.

191. I didn't know they had tried to reduce him to 500ui until I saw the Egress medical notes, but I do remember Seamus telling me the hospital ward wanted to take his personal supply of Factor off him.

192. At this point, I knew that the Haemophilia Clinic were telling patients, before attending clinic that they don't have to abstain from their Factor 8 for 48 hours before their bloods being taken. This could be how the Belfast clinic have been telling severe Haemophilia that their Factor level has changed to 2%, from less than 1%. This would characterise them as being 'moderate' haemophiliacs. Moderate haemophiliacs are normally only prescribed on demand Factor 8 treatment, and not prophylaxis treatment. Another way of saving money, again putting patients at risk.

193. If you are less than 1% in your factor levels, you can't suddenly become 2%? Severe haemophilia is hereditary in my family. All the men in my family are less than 1% (i.e. severe). Personally, I have had factor levels of 6% and technically a moderate haemophiliac. There is no way Luke or Eddie or any other severe haemophiliac are the same level as me, I don't get treatment despite the fact that I should. But there is no way Luke could even go once a week without factor? I don't understand how they can make these serious changes?

Legal Case

194. After Luke was diagnosed as a haemophiliac out of the blue in 2003, we were invited to the Belfast City Hospital to understand why this happened. From the meetings with the hospital, they weren't actually answering our questions. With everything that happened with Luke, and with Carla almost dying

because they wouldn't identify her as a bleeder, and the difficulty we were trying to find out what happened with my DNA test; this led us going to the High Court against the Belfast Trust in 2004.

195. The Belfast Trust kept wanting to settle out of court, but I wanted answers. My husband, Sid and I had to give up our careers when Luke was diagnosed. It was unbelievable the dirty tricks we experienced during this process.

196. The reason I am writing about this, is that we suspected we were being treated so badly by the Belfast Trust, because of the legal case we were pursuing between 2004 to 2015. During the legal case we had so many doctors and medical people supporting and protecting each other.

197. **GRO-D**

198. **GRO-D**

199. The judge was very sympathetic to my situation and it was a great relief to speak to someone who listened. The judge was very interested in Luke's diagnosis and the impact on Sid, Carla, myself and Luke. But the other side kept trying to keep me quiet. My children paid the price with their health for standing up to the Belfast Trust as the Trust continue to weaponise my children's haemophilia issues against them. I didn't get any answers. I didn't feel I couldn't keep going and eventually I did settle out of court.

Infected Blood Inquiry Oral Hearings

200. In October 2022, I watched the IBI live oral hearings. I listened to a HCV diagnosed person give oral evidence. She stated that after her hepatitis C diagnosis, she asked about treatment, as she was keen to get started and was told she would be assessed by a panel (infected persons panel) to see if she was eligible for treatment or not. This lady was astonished that there would be any question of her receiving treatment from the NHS, as they were the people who infected her.

201. This got me thinking, had Seamus, Eddie, Michael and others been subject to this type of panel? Were medical professionals deciding if their patients were worthy of treatment? If so, what was the eligibility criteria? Who set this criteria and who made up the panel? In Northern Ireland, was it Gary Benson, Neil McDougall, and GRO-D?

Complaints

202. I am making these complaints against the following; Dr Gary Benson and members of his team– Belfast city hospital, Haemophilia Clinical Director for NI;

- Dr Neil McDougall - Royal Victoria Hospital, Hepatology Consultant for Hepatitis NI;
- Dr GRO-D - GRO-D Belfast Trust;

- GRO-D for Haemophilia and Cancer Services;
- Dr GRO-D Belfast Trust;
- GRO-D HSCB;
- GRO-D HSCB.

203. We will not stop until this systematic campaign of abuse and catastrophic effect on Luke's life and health along with other family members by the Belfast trust is exposed, and challenged. I also call on the organisations responsible for the health and safety of patients to be more proactive in the protection of haemophilia patients, in Northern Ireland and make the safeguarding of these patients their highest priority, above the disruptive behaviour of clinicians, staff and management team, of the Belfast Trust, and the HSCB. In addition, to stand up to the coercive control faced when attempting to support patients like Luke.

204. Andy Burnham, said in his oral evidence to the Infected Blood Inquiry on 15 July 2022, that 'the safety of the haemophiliac community in this country has been grossly negligent, and would possibly warrant the CPS being asked to consider charges of corporate manslaughter'. I would absolutely agree with this and applaud Andy Burnham for his honest direct speaking, I would however go a step further as to say that charges of corporate murder should be brought (not just considered) especially in the case of my brother Seamus, my cousin Michael and the wider haemophiliac community in Northern Ireland.

205. At this point, we are left wondering when was the cut off point for contaminated blood? Was there still risk in 1999? How do we know when the blood has been safe from? We are worried as Carla had a blood transfusion in 1999 and whether she is safe. Also, is Luke safe from the infected Factor 8 blood products currently?

2022

206. Eddie had an appointment at the haemophilia clinic on 3 March 2022. At the appointment, in the treatment room, I asked them to make sure they were to take bloods for his Liver Function Test. Hellen Mason, the haemophilia nurse replied “we always do the liver function test as standard.” I knew this, but I was just making sure.

207. After we got his bloods taken we went into the Consultant, normally it was Gary Benson, but Eddie has now moved to a new Consultant. He is a lovely guy called Dr Gooding. Dr Gooding was very pleasant with Eddie, as we were chatting I asked Dr Gooding would he make sure Eddie, along with his GP, was sent a copy of his clinical bloods. Dr Gooding replied “of course they always are”. I informed Dr Gooding that it was not customary at this clinic to get a copy of your blood results. He was quite surprised but assured Eddie he would send a copy to both him and his GP.

208. I also asked him to check Eddie’s last set of bloods for the year. I had pointed out to him on the computer screen how the bloods were showing ‘blanked out lines’ (redacted). I asked “why are key parts of the liver function tests seem to be missing?” I also asked “how Eddie’s liver function bloods are always being reported as normal when he had advanced liver cirrhosis, cancerous cells and tumors?” I added that “this was the blood test that Seamus had relied on to understand the health of their livers.” Dr GRO-D just said “I’m not sure why.”

209. A few weeks later Eddie did receive a letter from Dr GRO-D with some bloods reported at the bottom, however at the very bottom of the page was oneline, reading “liver function bloods not reported”. Absolutely unbelievable, the liver function was the one blood test that we asked them to make sure was done. The one blood test that is done as standard. I believe it was by design that they left Eddie's LFT bloods out.

210. I contacted Helen Manson, the Haemophilia nurse at the Belfast City Hospital and asked “where are Eddie’s liver functions results?" She replied saying “we do our best and that it was a different system.” But it’s not a different system; they've been carrying out the clinical bloods in Altnagelvin for years. I believe the bloods have been done and they have not been given to us.

211. This resulted in a very heated phone conversation, with Hellen Manson. I told the Haemophilia nurse that I believed the haemophilia clinic was up to no good, I also told her that Eddie will not be going back to the haemophilia clinic. The clinic have been repeatedly harassing Eddie, sending him a letter through the Department of Vehicle Licensing Agency, (DVLA), stating he has to go to his GP and have his Liver function bloods done. But the DVLA have not done LFTs for years; they only do blood tests CDT by their own people and the blood test is only for people who have been convicted of drink driving.

212. This clinic has no respect, this had really upset Eddie as he doesn’t drink alcohol and hasn’t in 15 years or more and he doesn’t even drive anywhere, due to the pain of his haemophilia joints. They have also refused to respect his and the families wishes that no one from the Belfast Trust is to contact him without a family member being present, as they continue to cause him great distress for their own gain.

213. They sent a letter to Eddie in May 2022 from Dr GRO-D Consultant of the Belfast haemophilia clinic, has really disturbed us, but it has also given us some answers. Dr GRO-D wrote in his letter, that while they are a haemophilia clinic they are not liver specialists (**WITN2778025)**. Therefore, why on earth is this clinic allowed to get away with misleading patients into thinking they are safe when they are not safe? Why are they allowed to tell patients not to worry? “We see everything in the bloods.” They say “your livers are safe and you don’t need liver scans.”

214. In June 2022, the haemophilia clinic contacted a social worker connected to Eddie's GP practice, and sent him out to visit Eddie without informing us. They were trying to imply they were concerned about Eddie and that he could be at risk from his own family. Then again, in September 2022. The GPs social worker who attended Eddie's home found a very well taken care man, living in a beautifully appointed clean home with a well-stocked fridge full of healthy food. I spoke to the social worker after this and explained what our family was dealing with. The social worker said he had no concerns about Eddie's care by his family.

215. A few weeks later, Eddie received another letter from Dr GRO-D. In this letter, Dr GRO-D had set up an appointment for Eddie to attend Dr Ferguson's clinic in Altnagelvin for his liver surveillance. Again, Dr Ferguson is not a liver specialist, and his clinic is not a liver unit. I know that Dr Ferguson was unaware of these appointments being sent out on his behalf. He was only aware of doing 3 MRI scans for Eddie.

216. They don't want him back in the Belfast liver unit. GRO-D GRO-D Belfast Trust, sent a letter to Eddie stating 'he is no longer welcome as a patient, at the liver unit, RVH because of the GMC investigation'.

217. On 4 November 2022, I received a letter from GRO-D, Belfast Trust. On the Friday the 9 September 2022, I attended the Haemophilia Clinic with Eddie appointment, in my local hospital Altnagelvin. I wanted to speak with Helen Manson, the haemophilia nurse and I stood quietly in the public area. I waited until she was free and she invited me into to talk.

218. I gave her a signed letter from my family and Eddie, with regards to their contact with Eddie. I recalled that we have repeatedly asked that no one from the clinic contact Eddie without a family member being present as he gets very upset and distressed. I also told her that my children and I would email

signed letters (again), that no one in the haemophilia team is to discuss us or have access to our medical information without our permission. As this too has been ignored.

219. As we were discussing our family with Helen, a phlebotomist named GRO-D came into the room and started speaking to us in a very aggressive manner. She was discussing Luke, who she didn't know and I was having a private and confidential conversation with Helen. I asked her to leave and she then asked Security to assist her in removing me, Security came in and looked at us and then walked out. I finished the conversation and just left.

220. When I left there were no waiting patients nor did delays happen because of my attendance, the conversation took less than five minutes. I am not an aggressive person, nor have I ever attacked anyone verbally or otherwise. However GRO-D sent me a letter (**WITN2778041**; **WITN2778042**) claiming that I was with the staff and I am no longer welcome at the Haemophilia Centre. I am not allowed to take Eddie to the Hospital anymore. This is just another attempt to tarnish my reputation and intimidate me and my family because we have been speaking to the Infected Blood Inquiry.

221. For the last 4 years to date, the Belfast Trust and GRO-D have stopped my family from accessing vital health services (haemophilia care, dental care, physio care, social care, psychological care, cancer care and hepatology care). Due to my statements, and talking to the Inquiry, I am aware that this statement will have more repercussions on my family's health but I feel that what we have to say is crucial for the general public to know.

222. Thank you to Sir Brian and the Inquiry, I couldn't have made this statement without you all.

Exhibits

I have given a number of documents to the Inquiry Investigators, from the many, many documents that I hold. They have produced a precis of these documents and they are listed in the attached schedules below as exhibits. All the handwritten notes made by me have been noted.

I agree with the precis of my documents.

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

Name: Christina McLaughlin

Electronically Signed: **GRO-C**

Dated: 26/06/2023

Exhibit	Title	Dates	Precis
WITN2778007	Haematology Clinical Notes re M Conway (Hosp ref. AH 165691)	1st date 7.10.08	7.10.08 shows DNA 3.11.08 DNA 6.1.09 attended, no evidence of cirrhosis. Raised LFT alcohol intake related
WITN2778008	Page of a report re Mr S Conway Points 8 & 9 Patient attendance summary for Seamus	1st date 4.01.02 last date 16.06.08	A list of locations, consultant & DNA/ATT/ CND 35 entries - all BCH as location. Mixed Haematology Consultants 2 x ATT 2 x CND 31 x DNA (Did Not Attend) Various DNA have been highlighted Note entry re 16.06.08 is shown as DNA for Benson clinic.

WITN2778009	2nd page of same report re Mr S Conway Points 10 & 11	1st date 15.08.08 last date 03.04.18	A list of locations, consultant & DNA/ATT/ CND 27 entries - 12 at ALT & 15 with BCH as location. All with Benson as Haematology Consultant 6 x ATT 21 x DNA 2 highlighted for 2014 entries 2 marked in red ink with “Seamus was dying” & Alongside point 10 “Benson would not answer our calls for”
WITN2778010	Patient summary for Seamus Conway showing blood results	1st date 17.01.14 last date 24.05.18	Entry number 15 (note series starts at number 4) Asterisk in red pen “27 April 2019 why are ALT’s missing but shown on sheet below Altnagelvin bloods” N.B. ‘ALT/SGPT serum levels’ are blank for all 14 entries ‘ALT’ are blank from 21.11.2014 (number 8) to number 18

WITN2778011	Belfast City Hospital Haemophilia C Dept. re Seamus Conway	Clinic date 16.06.08	To Mr Mullally, Consultant Dentist, RVH From Dr Gary Benson Requesting Mr Mullally to see Seamus who is HCV+ Handwritten in blue "GB, has only shown Seamus attending clinic once this year on 21.11.08, I took Seamus" & "Clearly he has attended on 16/06/08. Where is bloods" & in black ink "DNA*"
WITN2778012	Radiology Report re Seamus Conway from Altnagelvin hosp. Page 26 of 29 (via Egress)	N/A	1 - "Re previous imaging abdominal. x-ray of 23.10.10" 2 - "Findings: A destructive lesion seen in the right iliac

			bone. Please refer to subsequent CT abdomen report (30.04.18) for detailed comment on right iliac bone lesion." Handwritten (arrowed to 1) "Where is this xray? There is only 3x reports in file, for the date 23.10.10 attached. (23.10.10 report missing) Handwritten (arrowed to 2) "This is 4 weeks before Seamus died, looks like a bone lesion was seen on Seamus's pelvic bone (iliac bone) from 23.10.10"
WITN2778013	Altnagelvin Hosp In Confidence letter To Dr McCallion (GP) at Cityview Medical Re Seamus Conway from Dr Mark Robinson SHO in Orthopaedics (For Mr Charlwood)	28.03.14	Text mentions: Anaemia and early signs of Alcoholic liver disease - both highlighted and handwritten above is "What is Alcoholic liver disease. Why is it not Hep C liver disease. Seamus was not an (alcoholic).

Exhibit	Title	Dates	Precis
			Also highlighted is Clinic date - 26.03.14
WITN2778014	Western Health Trust Detailed trauma	Not dated	These are handwritten doctor/ nurse notes re a “fall in the early hours of this morning” and detailing injuries. Details at bottom of page which have been highlighted. Hepatitis C, Hypochromic (illegible), ?early ALD - as per Dr Benson. Arrowed to Severe Haemophilia A is Handwritten by CM “Previous multiple bleeds into ankle & knee joints” and “On demand Re (illegible) as required

WITN2778015	'CT Abdomen & Pelvis with contrast' re Seamus Conway request by Altnagelvin Hosp	Performed 30.04.18	Highlighted parts: "I note from the ECR" "cirrhosis secondary to HCV" "according to the known cirrhosis" "according to known HCC". In the conclusion Section: "Cirrhotic liver"

WITN2778016	Patient Summary re Seamus Conway	1st date highlighted 16.03.2011	Under a section headed: LFT Cumulative 4 dates highlighted 16.03.11, 22.07.13, 28.08.13, 17.01.14 All have an asterisk* next the AST serum level. ALT/SGPT serum level & Serum gamma GT level. Handwritten: "Asterisk (*) is a sign of abnormality" With a line to ALT says "signs of cirrhosis" Next to highlights says "Where are ALT's" "Why are they blanked out"

WITN2778017	AFP Cumulative results. Typed for Edward Conway but this has been crossed out in pen	1st date 13.04.19 Last date 11.09.20	Prepared for GRO-D GRO-D

WITN2778018	LFT Cumulative test results for Seamus Conway	1st date 17.01.14 Last date 24.05.18	15 date entries Numerous handwritten notes: Entry 6 date 15.09.14 circled in red “not in notes” Entry 7 date 11.11.14 circled in red and ticked Entries 9 & 10 for 12.02 & 12.8.16 both ticked in black Numerous out of range entries highlighted There are no results at all for ALT/SGPT serum level - starred by CM. ALT levels stop being entered after entry 8 (2.11.14) - starred by CM. All are well above range Then entries commence at entry 9 for Serum ALT level. All are well above range. Series of dates on the left, the last for 15.02.18 for Immunoglobulins is circled in black

WITN2778019	Altnagelvin Hosp. Lab result for Seamus Conway	Handwritten “2018”	Numerous details highlighted and marked either “high” or “low”. Alk Phosphatase is *383 for a range of (30 - 130). Handwritten “Signs of L/cancer/cirr” also “4 weeks before Seamus died” “These were the bloods, Seamus was dying”. N.B. others well above range shown in (): AST *141 (10-40) ALT *92 (10-35) GGT *237 (10-50)
WITN2778020	Altnagelvin Hosp. Lab result for Seamus Conway	Handwritten “2014”	Blood test results with numerous marked with * as being out of range. Handwritten these * are highlighted by CM

WITN2778021	LFT Cumulative results for Edward Conway	1st date 26.02.16	Various test results for 4 dates 26.02.16 to 14.09.18 Handwritten: # next to AST serum level and Serum ALT level. 3 entries highlighted as being out of range in the Serum ALT level column. Also highlighted Prepared for GRO-D on 28.11.18
WITN2778022	AFP Cumulative results for Edward Conway	1st date 13.08.18	Handwritten: Highlights on Copy only. Do not file 2 dates 13.08.18 & 14.09.18 *Denotes abnormal results Prepared for GRO-D GRO-D on 12.2.21

WITN2778023	Letter from Medical Directors Office Belfast City Hospital Signed Mr GRO-D GRO-D	Not dated but apologises for late reply to her letter of 28.10.21	Page 1 of 2 To CM , Edward Conway Letter re treatment location for Edward Highlighting in third paragraph Due to CM complaint to GMC Dr GRO-D will no longer provide care for Edward

WITN2778024	As above	As above	Page 2 of 2 Undated marked 2. Signed by Chris Hagan, Medical director, CC Mr Edward Conway. Highlighted "I note following Dr GRO-D's letter on 24.10.2021". Claiming Edward Conway cancelled his appt. with Dr Ferguson at Altnagelvin Hosp on 8.11.2021. States due breakdown between you (presumed CM), it wouldn't be appropriate for Dr GRO-D to meet with you or Mr Conway again. Please rearrange the appt. with Dr Ferguson at Altnagelvin Hosp. Asks not to write to Dr GRO-D as he has

			discharged his duty in handling Mr Conway.
WITN2778025	Letter from Belfast City Hospital, Haemophilia & Thrombosis Centre to Edward Conway	Undated	After an investigation to establish why there was Liver Function Test (LFT) result following a recent visit. Further down the line “The Haemophilia Clinic is not a substitute for the Liver Clinic because we don’t have the same level of expertise in this area of medicine” This has been highlighted by CM with “OMG” circled next to it. The next paragraph had numerous highlights by CM talks about “Hepatitis being successfully treated back in 2019”. CM has handwritten “Don’t believe it was cleared”

WITN2778028	Doc title from CM GMC Rule 12	1.7.21	To CM from Niall Kelly, Complaints and Review Case Officer. Re CM request for a Rule 12 review [GMC Fitness to Practise], asking if she has submitted all the information she wishes to be considered, this must be done by 15.7.21. Let him know if this is not feasible.
WITN2778029	GMC Rule 12 Correspondence	10.7.2021	From CM to Corporate Review Team. Reply to WITN2778029. Starts "Everything we have to say as a family you can read in the attached statements". Relates that Hepatology and Haemophilia Units of the Belfast Trust are actively trying to kill off blood contaminated haemophilics in Northern Ireland by lying about scan and blood results plus other similar allegations

WITN2778030	Email from Helen Tebbey (GMC) to CM	9.3.2021	"We don't need any more information from you at this stage, we'll let you know if we do. The next step will be writing to the doctors and providing them with copies of the information you have provided"... "Once we have had a chance to review that we'll consider then whether we need to get copies of Eddie & Seamus' medical records"
WITN2778031	Email from CM to Helen Tebbey (GMC).	21.6.2021	"In February I told you that I had a lot more information I wish to send, you told me not to send anything more yet and you would come back to me" Further that previously told me to wait to send more info but they (GMC) never came back to CM. CM asks why this is not being taken seriously. CM asks Helen to enable the Rule 12 to be activated.

WITN2778032	Letter from Gary Benson to Dr P Gardiner	Clinic Date 11.2.11	Clinic date 11.2.11 re Seamus Conway. Requesting he review this patient as an outpatient for treatment re steroid injections. Notes Seamus is a poor attender at his clinic.
WITN2778033	Letter from Gary Benson to Dr J C Stone (GP)	Clinic Date 4.10.11	Clinic date 4.10.11 re Seamus Titled - BCH (Altnagelvin) Clinic. Notes that Seamus did not keep his appointment today. At the bottom of the page it shows Daniel J Roddy with 2 reference numbers. Annotations made by CM “Notes sent to us for Seamus” “Seamus was not sent an appointment on this date” (with an arrow to 4.10.11) “This is not Seamus’s hospital number, must be GRO-A” (with an arrow to an Alt No.)

			At the bottom of page the name GRO-A GRO-A has been highlighted by CM with “Wrong patient not Seamus, GRO-A ”
WITN2778034	Letter from Gary Benson to Dr J C Stone (GP)	Clinic Date 4.10.11	Same letter as above but with the Alt no. redacted and another handwritten underneath. Also has GRO-A GRO-A with 2 reference numbers at the bottom. Annotations made by CM “Egress Copy” Sent to CM by IBI “Notes sent to Inquiry” “Belfast redacted this copy but not our copy” “This is Seamus’s Altnagelvin Hospital Number” Seamus’s Altnagelvin Hospital number written in pen (Highlighted) by Belfast Trust.
WITN2778036	Altnagelvin Hospital - Volume 1 of 2	N/A	Report section (for laboratory use only) Re Seamus Conway age 6 ½. Handwritten is “Tina This would be 1980 or 1979”. Various result numbers are marked * as abnormal result. The entry for ALP is 48 and 12.1 have been highlighted as is the word abnormal

WITN2778037	Clinical Notes	First entry entry 2.10.14	Re Seamus Conway handwritten medical notes. Highlighted: The date 2.10.14 and an entry which "Hep C (1980)" There is also a yellow post-it note with: (2014) A/N Hep C from 1980
WITN2778038	Royal Victoria Hospital Haematology Day Clinic	First date - Date of specimen 3.11.95	Highlighted: Dr E.R Butler AST 147* & ALT 171* Date of specimen 3.11.95 Hand written: "Signs of liver disease, Tina"
WITN2778039	N/A	N/A	Post-it note with "Seamus A/N 1979" The paper is out of focus Handwritten "No abnormality" CM wanted to show that Seamus appears to be HCV- in 1979 but HCV+ in 1980. Indicating that he was infected in 1980.
WITN2778041	Letter to McLaughlin from GRO-D (Belfast Health and Social Care Trust) (Page 1)	31.10. 2022	Discusses breakdown with clinical relationship with the McLaughlin family. Reported by several staff that during a meeting at Altnagelvin Hospital, Christina raised her voice and spoke aggressively.

WITN2778042	Letter to Christina McLaughlin from GRO-D (Belfast Health and Social Care Trust) (Page 2)	31.10. 2022	Notes that Belfast Trust has a Zero Tolerance approach to aggression and violence towards staff members. Therefore, Christina is no longer permitted to attend the Haemophilia Clinic, North West Cancer Centre. Caroline states that another family member can bring Edward to the Centre.
WITN2778043	Letter to Christina McLaughin from GRO-D (Belfast Health and Social Care Trust)	31.10. 2022	Letter states that patient confidentiality statements are not available as Christina, Luke and Carla are no longer patients.