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Witness Name: GRO-B

Statement No.: WITN0610010

Exhibits: WITN060010-012

Dated:

INFECTED BLOOD INQUIRY

SUPPLEMENTARY STATEMENT OF GRO-B

Further to my written statement dated 2 April 2019, and in support of its content;

I, GRO-B, will say as follows: -

1. I write this statement with input from my wife, GRO-B, and my daughter, GRO-B.
GRO-B: D.
2. My son GRO-B: S has very sadly passed away now, on GRO-B 2020. His Death Certificate states that the cause of death was: 1a) Mesothelioma; 2) Hepatitis C, Depersonalisation disorder, Anxiety, Thyroidectomy, Psoriasis, Leukaemia.
3. To expand from my previous statement, we have had a running battle with the mental health provision provided to S. Due to the Hepatitis C (HCV) treatment, after 18 months of it, S's mind was disturbed. That was the start of his mental problems. The mental health support is so poor here in Essex, he was neglected.
4. S had a mild HCV infection at Great Ormond Street Hospital (GOSH) under Mr Novelli. At 16 he should have left GOSH but they kept him on for a few years as HCV in children and adolescents was Mr Novelli's speciality. So S did not leave GOSH until he was 18 or 19 when he was transferred to the care of UCLH as an adult. There as a patient of Professor GRO-D his infection was immediately classed as severe, (two different opinions from two different consultants at two different hospitals).
5. I never had a lot of confidence in Professor GRO-D who after starting the hospital's HCV programme ruled supreme in his domain. No one would challenge him, at 82 "he was well

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past his prime" (not our own words). I am sure that [S] should not have been put on that drug treatment at that time. But as a parent you believe these people and for your child tend to grab at straws. So in a matter of weeks of transferring to UCLH [S] did a 6 month course of Interferon and Ribavirin which did not work and his future was cast.

6. He then contracted thyroid cancer and the left lobe of this thyroid was removed.
7. It was always the intention to go on a second course of treatment to get rid of the HCV infection when he was strong enough. But [S] went through several physical and mental problems and it was spring 2007 before he went on a 12 month course of Interferon and Ribavirin in both injection and tablet form. Followed by a six month period for the effects to stabilise.
8. By October 2008 he had expelled the virus, but the after effect of the powerful drugs really sent him out of his mind. They were profound side effects. The doctors said he must have been mentally ill before the Interferon, but he wasn't, he was happy and stable.
9. He never had any mental health problems before he had the HCV treatment. The second round of treatment was when he really 'cracked'. He was regularly monitored for Hep C and cancers at the Long Term Leukaemia Follow Up Clinics.
10. After this in early summer 2012 a swelling was noticed in his neck. Then the surgeon at UCLH Dr Kurzwinski said he needed an operation to remove a malignant parathyroid gland. This turned out to be non-malignant, but the damage to his wellbeing was done.
11. [S] said that after the operation, when he was coming-to, he heard the surgeon saying, "We should've left this one alone." [S] only told us this several years later.
12. They sent [S] home a day after the operation, the UCLH staff telling us to build up his calcium levels. They gave us calcium and other medicines to administer when we got home, these instructions we followed to the letter. Two days after the operation, he collapsed because he was being vastly overdosed.
13. That was 23 March 2013, when we went to A&E at Colchester Hospital. When we took him in, the doctors said it was good that we did, because he could have died due to the medicines he had been given. He had been overdosed with too much calcium.

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14. There was a really lovely doctor at Colchester, Dr Mahmoud. He was a really nice man; he took [S] under his wing. They let him out on 29 March 2013.
15. Within 2 weeks his calcium levels stabilised but his nausea did not go. It took months to get his dose right but he was never right in the head again. After this operation [S] started getting depersonalisation.
16. Unfortunately UCLH could not help us a great deal at this time as they had no mental health department, and we had virtually no help from our local mental health authorities. So as a consequence [GRO-B]. His general health and anger now gradually grew worse.
17. The interferon was a killer for [S], I have never seen a person that angry. At about this time during one appointment at UCLH, he blew up at [GRO-B]. They sent him by taxi directly to the Lakes Mental Health Hospital in Colchester, a place we had tried for months to get [S] admitted to. The Lakes sent him home the next day saying there was nothing wrong with him.
18. [S] was due to go to [GRO-B] University to study Media, we think he could have managed the course. He had just three months of a three year media course to go at Colchester Institute but his surgeon Mr Kurzawinski said his parathyroid operation was urgent and could not be delayed (see comment in paragraph 10). He was never well enough to resume his studies.
19. He started living with some friends but he was asked to go. He would not come home because he said he could only remember the bad times, and associated home with pain. So we bought a flat for him in the centre of [GRO-B]. At that time we had a good sitting tenant. I did not think [S] was ready to fend for himself and had bought the flat for his future use, but [GRO-B] and [GRO-B] overruled me and [S] went into the flat.
20. The flat became a tip, he slept on the floor, and he broke whatever furniture and equipment we put in there for him. He always held it against us saying we had forced him out, but we had not. But he had proved me right, he could not look after himself, but he still would not come home.
21. The local mental health support was non-existent. I wrote a letter of complaint to the head of North Essex Mental Health Services. We had meetings at their Colchester HQ, but it was all a paper exercise. He received no help, not a health worker to check on him, organise his

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medicines. The two co-ordinators he 'was' given were useless and downright cruel. One left him sitting crying, on the kerb in the High Street, and simply walked away. We were alerted by a concerned passer-by who phoned us at home.

22. S did not like the flat or staying in it, so he wheeled his books and writing around with him in trolley. He would go to the library and use the computers there. This made him a target for the homeless, especially the crooked homeless. They used to rob him, and nearly every day would take his phone and make him buy it back. They tried to make him buy drugs, they even put crushed paracetamol in bags through his letter box and threatened to beat him up unless he paid for it.
23. Once he was robbed and went straight to the police. The desk Sargent said he saw the incident on CCTV, but the police said they couldn't do anything because they could not hear what the thief had said.
24. One particular violent homeless person, well known to the police, once broke into S's flat and was standing over S who was sleeping on the floor, and demanded money at 2 am.
25. Due to his mental state S thought he could placate his tormentors by giving them a film show. He was receiving benefits and never had to pay me rent so he spent a lot on films, projectors, music etc. After the show they took all his equipment for drug money. The homeless used to often camp on his doorstep and bother him and his neighbours.
26. He was beaten up by young thugs twice in early evening in the centre of town. The police brought him home to us about half a dozen times, but he would not stay here so they took him to hotels.
27. He started to hear voices at about this time, and afraid of people breaking in he began to sleep in the loft above his flat. But still he had no official support. One team came from some mental charity we had been put on to. They visited the flat and said you are ok, and do not qualify for any support. That was not true both he and it were in a terrible state. At the time S hardly washed, bathed, and shaved. At this time his fingernails were about 1.5 inches long.
28. S visited several GPs in town and probably expected too much of them. He had built up an idea of what tablets he needed, he thought he knew what he needed and did not always listen or understand their position. So one by one they tired of him and he would drift to a new GP.

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29. Finally, he found a new lady GP who seemed promising. She said she would give him the drugs he thought he needed, but then she went on holiday without leaving him a prescription. Unfortunately in frustration he went to see her at home. She then said he was stalking her (he was not of course and it only happened once), and saw to it that he was banned from all GPs in and around [GRO-B] I do not recall the GP surgery she was from.
30. He could only order his perscriptions over the phone. It worked quite well but there was no ongoing monitoring as he saw no GP. Shortly after this he developed fluid in his lungs which turned into pneumonia. He was hospitalised after seeing A&E at Colchester General from 10th May to 14th June 2019, when he returned to the flat as he still would not come home.
31. [s] was again admitted to Colchester General on 21st August 2019, he was very ill now. We were called in twice in this last week of August when they thought he was close to death. On 3rd September he was transferred to [GRO-D] when they had a space and he stayed there until 18th September 2019 when he returned to Colchester General. Discharged from Colchester General to his flat on Sept.25th.
32. Whilst in [GRO-D], on 4th September they did an operation to empty, clean, and biopsy his lungs. During this procedure he actually 'died' and with difficulty they revived him, [s] afterwards said he suffered an out of body experience at this time. But the results of the biopsy taken at this operation were then lost by [GRO-D] until discovered by accident on December 5th 2019 and passed on 3 months late to Colchester General. By which time [s] was back in Colchester again, having been re-admitted via A&E on 21st November 2019. The biopsy told us that he had Mesothelioma and had 6-12 months to live.
33. [s] remained in Colchester Hospital until being transferred to [GRO-B] Care Home on March 16th 2020. He had been moved from the hospital as they needed the beds due to the growth of Covid 19 and because he would be very susceptible to infection.
34. Mesothelioma is a long term illness caused by access to asbestos fibres many years before, often 20 to 30 years. We do not know where he contracted it but possibly from GOSH or Barts Hospitals where they treated his Leukaemia in April – May 1990, both were undergoing big building work at that time. He was also in Queen Elizabeth Hospital Hackney in January and February 1990 when they had started decommissioning that place.

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35. When GRO-D lost S's biopsy results their consultants maintain that it made no difference to his prognosis, This is what Mr. GRO-D his surgeon said when we met him in December 2019, and he was genuinely upset and sorry. But I believe a good Barrister could argue differently, that the lost three months did delay any possible treatment for S benefit. I have forwarded to you the results of Papworth's internal audit.
36. S made a great impact on the lovely people at GRO-B care home, for the first time in years he was with people loved him and were kind to him. But the cruel fact was that Covid played hell with those last few months. We could not see him indoors, we had to stand outside his ground floor window which only opened three inches so as to prevent the inmates from escaping and only allowed us to touch fingertips. When summer arrived and covid restrictions reduced a little we were able to sit with him outdoors masked and gloved.
37. We knew the end was near but thankfully when it came it was very peaceful and quick. The nurse with him said he said he did not feel very well and wanted to lay down, he held her hand and just slipped away. She said it was the most peaceful thing she had ever seen in her life. She had been on her own with him holding his hand, yet she apologised to us for not telling us earlier but we were glad she stayed with him till the end. We drove in but missed his passing by about 20 minutes.
38. Ironically enough Covid rules were relaxed slightly just the day before he died. The care home is very close to GRO-B's seafront, so the carers took him to the seafront in a wheelchair. He wanted them to push him on to the beach and into the water but they couldn't because it was mostly shingle there. As a consequence they set up a fund to purchase two suitable wheelchairs to do just that. We gave some money but one person gave £4000.
39. Since his death GRO-B's mental state has deteriorated. She gets upset and has such anger, it is sheer rage, she can be unrecognisable and it comes out of the blue. She doesn't eat much but drinks too much, "why did it have to be my son" she shouts almost every day. His passing has had a huge impact on her and therefore an impact on myself.
40. Four weeks before he died it was his 34th birthday they put on a movie show come party at GRO-B showing his favourite film "Ghostbusters", our 3 year old niece GRO-B attended and she is now a real Ghostbuster fan.
41. GRO-B's husband GRO-B contacted a company that has an exact replica of the Ghostbusters car used for films and adverts and asked them if we could use their car as the hearse for

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[S]'s funeral. They readily agreed, they have never done this before and probably will not again. Just a week before the funeral the car had been flown to South Africa for an advertising film. The whole thing was brilliantly done. The lights and the sounds it caused a great stir, even the driver had on a ghostbuster uniform, it made the funeral almost a happy celebration of his life. I know [S] would have approved. It even caused a brief moment of fun to people waiting for other funerals at the crematorium.

42. [S] had planned his own funeral, some of his own poems and his choice of music, it was lovely, but only 15 people were allowed in. Due to covid at the last minute the wake was cancelled so we served coffee and biscuits out of the boot of our car instead, it was just right.

43. They were going to do a post mortem, [GRO-B] was adamant that they should not cut him up again. The coroner was very kind, as they had plenty of medical evidence he said he would not do one. The record of inquest is exhibited as [WITN0610011].

44. There were several incidents for which some would sue for. [S] missed out on a class action for compensation for Hep C by 3 weeks in 2000, Pneumonia caused because a doctor said he was stalking her when he wasn't, Contacting the asbestos somewhere, and lastly the missing biopsy for three months at [GRO-D].

45. The lack of mental health support of any real value was another issue. I wrote to the General Medical Council on 8th October 2018 but got a poor response. Exhibited as [WITN0610012].

46. I wrote to [GRO-D] not to complain of their treatment of his illness but more to complain about the results of the biopsy being misplaced for three months. Their reply dated 21st April 2020 is exhibited as [WITN0610013].

47. We have had nothing but pain and not a lot of help from UCLH, which is disappointing from a major London teaching hospital. But from our local Colchester Hospital which at that time was suffering a very bad press we had the very best of care.

48. The impact of all this has been bad for daughter [GRO-B] too. She pulled all her eye lashes out whilst this was going on. Prior to the last year [S] was so angry and difficult, but at the end they became as close as they were as kids. Towards the end he would lay his head on her lap and talk. [GRO-B]'s daughter [GRO-B] misses her uncle [S], he never ever hugged her because his depersonalisation made him feel she wasn't there.

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49. It is all so very unfair, especially as it could have been prevented. I have heard that there was a hep c test which other countries used, but good old UK would not use it and had to develop our own. It was during this brief 15 months or so period of not testing blood used for transfusions that [S] contracted Leukaemia and received 70 odd transfusions of various blood products.

Statement of Truth,

I believe the facts in this statement are true.

Signed

GRO-B

GRO-B

Dated

23rd March 2022