Witness Name: George Constantinou
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Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GEORGE CONSTANINOU

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 February 2020.

I George Constantinou, will say as follows: -

Section 1. Introduction

1. My name is George Constantinou. My date of birth is GRO-C 1958 and my address is known to the Inquiry. I am married and have a daughter.

2. I can confirm that I have chosen not to have a legal representative with me at my interview with the Inquiry Investigators on 5 February 2020 and that I am happy for the Inquiry team to take my statement.

3. I am thalassaemic and require regular blood transfusions to manage my condition. It was via one of these transfusions that I contracted Hepatitis C. I intend to speak about how my life has been impacted by

contracting this disease, and especially, how its treatment and long-term physical damage have affected me and my family.

4. I was initially reluctant to be interviewed by the Inquiry but was asked by GRO-A another thalassaemia patient who has provided a statement, and he convinced me we have to do something.

5. I was a founding member of the United Kingdom Thalassaemia Society (UKTS) and served on the board for over 40 years but have now retired. I now work with the Thalassemia International Federation (TIF) helping patients globally. For example, just last week, I was called to a conference in Athens on Hepatitis C and I will append that presentation to this statement.

6. I was born in 1958, a time when no one knew about thalassaemia and doctors did not understand how to treat the condition. The family pediatrician who first looked after me told my parents "at least you have three sons", "all we can do is keep him comfortable". They did not expect me to live past my sixth birthday.

7. With little knowledge about my condition by clinicians in Cyprus, my parents travelled to Greece, England and France to find out more information about the condition. However, my parents were not satisfied as they received no answers. It was only after we were contacted by a wealthy friend who told them about a brilliant doctor who knew about thalassemia, that my parents managed to obtain help for me.

8. To provide some background about thalassaemia, at 18 months, the spleen becomes enlarged due to it destroying the blood your body produces. The doctor that my parents were put in touch with, Dr Fanconi, removed my spleen and started a series of blood transfusions, which went on to become the accepted treatment for thalassaemia.

9. However, a side effect of transfusions is a build up of iron, which the body cannot get rid of naturally. It was the iron overload that would eventually kill you. So, a drug was produced to alleviate this; Desferioxamine, also known as Desferol. At the age of ten I started this treatment, which was an injection, which kept me alive for longer than I was expected to survive. However, it was eventually discovered that this treatment was insufficient. It was improved by changing the injection into a slow releasing pump, which would be more efficient in removing the excess iron.

10. With a want to help other thalassemia patients I helped establish the United Kingdom Thalassaemia Society (UKTS) in 1976. My first aim for the society was to fundraise in order to sponsor a company to produce an infuser. We turned to financing, as no one cared about our condition. It was what people called a "small society problem", but we persisted regardless.

11. Most urgent was the need to produce a pump which would slowly release the iron chelator through a needle. These pumps would have been useful for treating diabetic patients (due to the benefits of slow releasing insulin). At the time, diabetic researchers were looking to make a pump for their patients, however, were unwilling to test it on their patients due to the dangers of infusing too much insulin.

12. So, for many years we went without Chelation (the process through which iron is removed from the body). This eventually started affecting the glands which, in turn, made us diabetic. Alongside this, patients also died from heart disease, mainly due to the iron build-up. Many of my friends died.

13. Even with the medical developments the treatment was arduous. We had to dilute five bottles of white powder, put the syringe in the pump, and then inject it for 18 hours a day. The problem was not so much movement, it was more the pain that arose in the stomach, in the

arms, and generally everywhere. There was a time where I could not even touch my stomach due to the pain.

14. From 1986 to 1987 we worked very hard. Some clinicians said they had an option for an oral chelator called Deferiprone, but needed money for animal trials and then clinical trials. We, as the UKTS were able to raise £1,000,000. When those clinical trials began, that really was the first turning point.

15. The major advancement in the understanding of thalassaemia came when researchers began to seriously worry about the impact on the heart and the liver. The introduction of the MRI was able to show us what was occurring in these organs.

16. Initially, a Ferritin test was used to regulate a patient's iron and chelation. The introduction of MRI was the second breakthrough that would allow thalassaemia patients to live to full health. We still need transfusions though and there are currently trials for gene therapy.

17. The biggest problem now is the cumbersome and expensive treatment. Here, in the UK, the problem is less, due to the smaller number of patients, yet, in Thailand, India, Pakistan, Bangladesh and Iran the issues are much greater. In India, for example, 100,000 are born every year and their healthcare system cannot cope.

18. GRO-A and I are the oldest patients, and it's by sheer luck that we are still here - most of my peers - I buried them. As far as thalassemia goes, now the younger generation, they look physically normal, it has been a journey and it was difficult.

19. In addition to my work for the Thalassaemia Society, I went to school and then went on to University. I became a hotel manager at the Dorchester, in London. I then returned to Cyprus and ran a hotel there. I then moved on to work in finance for a tour operator. I will discuss later in my statement, how Hepatitis C affected my finances and career.

My thalassaemia

20. My parents did not treat me as though I was different. If you have a chronic condition and you have not learnt to handle it, you will die. I am glad my parents instilled the fighting spirit into me. I was not pampered or wrapped in cotton wool. I believe many of my peers did not have that strong support at an early age. Parents react very differently when their child is ill. I was treated in the same hospital, we all have the same thalassemia genes so I cannot think of any other reason why I survived and they did not.

21. My thalassaemia is at a level of total severity. So, I need two units of blood every three weeks. It has more or less been the same for a long time now. Initially, I was treated at University College, London (UCL) but I was moved to the Whittington Hospital, London.

Section 2. How Infected

22. I do not know the exact date of my infection with Hepatitis C. As I have described above, I need to have transfusions constantly, so none in particular stand out.

Section 3. Other Infections

23. I did not contract any other infections as a result of my transfusions.

Section 4. Consent

24. As thalassaemia patients we are constantly updated on our medical status. We use our test results as a motivator.

Section 5. Impact

25. My first recollection of being told something was wrong was in the late 1970s. My clinician, Dr Beatrix Wonkey, was wondering what was happening with my liver since the enzymes were fluctuating out of control. She was a haematologist, specialising in sickle cell disease and thalassaemia. She cared too much and therefore took note of the liver problems. She eventually found 65-75 patients of her patients had contracted NANB Hepatitis, as it was then known. She was not a liver specialist, so needed someone in that area of speciality to work out what was happening. She managed to track down a professor, Dr Geoffrey Dusheiko, at the Royal Free Hospital, London who followed up on her concerns.

26. It was not until the mid-1980s that she started to suggest possible treatment options. I do not remember specifically; all I recall is her beginning to discuss NANB as part of our treatment and how to get rid of it. I recognised that as one of the oldest patients I needed to be one of the first to try possible treatments, in order for younger patients to follow.

27. I was given very little advice on what treatment would be like, simply due to the fact that it was unknown. All they really knew was that sexual contact was not a problem unless there was a transmission of blood. Not knowing possible effects was something that made people cautious. Eventually we would organise conferences for patients specifically looking at the treatment for Hepatitis - but initially it was through word of mouth. The most severe patients would be told by their doctors, who would pass the information on.

Effects of the Hepatitis C treatment

28. My clinician was understandably very concerned about the hepatitis, so started us on the first treatment of Interferon. This went on for a long time...too long, because my doctor was keen to get rid of it, to limit the impact on the body.

29. In terms of side effects, I had them all: fever, tiredness, nausea and suicidal tendencies. I was exceedingly anxious and stressed as I was also trying to keep my job. I would inject myself on Saturday night because I worked Saturdays. That was me done until Monday. This went on for many, many months

30. The loss of concentration was the worst. I had a young daughter and I could not be a father. Plus, I still had to keep up with the thalassemia treatment

31. After the initial treatment was unsuccessful, I began Pegylated Interferon. I was on it for 18 months, which was absolutely awful and I still had the same side effects. The break between the first and second round was not long enough. You can imagine the anxiety waiting for the results, only to be told it did not work.

32. With the Pegylated Interferon and Ribavirin, the biggest problem was the haemolysis. It was impossible for me to chelate the amount of iron I was producing. I had to chelate every six days. It was a losing battle during what was already an incredibly challenging time. It brought on a loss of appetite. I lost 12 kilos and I am already a small man. My doctor would joke "next time bring George, along with his clothes".

33. After the second round was unsuccessful, I had two more treatments with Pegylated Interferon and Ribavirin. Telprevir was also added. Every six months we would try a new treatment but nothing seemed to work. It cured many people, but not me.

Long term physical damage caused by the Hepatitis C and its treatment

34. More recently, I had an ultrasound and the hepatologist found that I had two lesions on my liver, known as a hepatocellular carcinoma. This is a type of liver cancer which required ablation.

35. The first ablation was in 2012 and in 2013 it was identified again. This time, the tumour was slightly larger than before, and again, we went for ablation. During this procedure, which is far from simple, they found more and told me that I needed a liver transplant. A transplant of the heart is ten times easier. I thought I had come to the end. I still had a young daughter and thought I was still too young but I started to organise any financial loose ends.

Liver transplant

36. I underwent my transplant in June 2014 at the Royal Free where they had never conducted a transplant on a thalassaemic patient before. There were certainly a few scary moments. Have you ever spoken to a surgeon? — They are not the easiest to talk to. They want you to have low haemoglobin, mine was of course low and so they were happy. After the operation, as I was beginning to come around, I asked, how about a blood transfusion? I was told, don't worry about it, you will make your own blood. I thought, shit, this guy is going to kill me.

37. It was a very big challenge for me and my wife. After a week of tests, they sit down and they decide what the outcome will be. For me, things did not work out completely perfectly. My hepatic artery collapsed which means the liver is not being supplied properly. So, they put in a stent, which also collapsed. Then, it was a further six hours to reconstruct the duodenum and the bile duct. Put simply, the flow into the liver did not have the force to clean out the waste it was taking in. I was in and out of hospital with infections after that: September 2014, 25 days in hospital, January 2016, six days, and then back again in June 2016.

38. In 2017 I was down to 46 Kilos, nine kilos less than normal. This, out of everything, was the most horrible. They put a drain into the liver and I was in the hospital for 20 days. I had 12 units of blood in eight days.

It was horrible internal bleeding. I have never felt so awful. If I stood up my head would spin. It was truly scary.

Present day health

39. Putting the drain in helped my liver. The main thing that has changed is that, in the past two and half years, the liver is being supplied through different peripheral veins. Despite this, I am exceedingly careful and wouldn't do 80% of things I used to.

40. Despite my condition, I am well-travelled. I was the founding member of the International Thalassaemia Federation, a role that has taken me to India four times and to Azerbaijan (before its modern establishment).

41. Now, I cannot do what I love, which is to empower patients, as I can never be too far away from the Royal Free, which is exacerbated by the fact that travel insurance is very hard to obtain. Recently, I was invited to go to the United States, they had $1,100 set aside for my travel and it would have been $1,800 in insurance for four days. It is financially prohibitive. Now, I mainly travel within Europe and carry my passport on me at all times.

Effect on my finances

42. Hepatitis C caused me to lose my job. I was a financial controller and I used to earn quite a lot of money. All my life I have tried to not allow my Thalassemia to interfere, but with Hepatitis C I felt like I had no choice. I felt like I was begging for welfare when I applied, which was one of my lowest moments. I was on £60,000 before bonuses and now it is zero.

43. After I lost my job, I started my own consultancy and built up three companies as clients. But with all these infections from the liver

transplant, I felt like I kept losing my time, so I had to fold it up. It is very painful to recall.

Effect on my family

44. With the Ribavirin, I was rendered useless. When you are in that state you need people to hold you up and support you. It affected my relationship with my daughter in terms of the time I could spend with her. I remember going to her Greek school dinner dance and having to administer my injection at 9:30 pm, so I went to the car to inject myself. By the time the party ended, I was in shivers and dozing off, which is not something you want your daughter to see. My wife had to take care of the family and hold it up. But it shook her confidence, and that takes a lot.

45. I would never let my daughter see me inject. I remember once, having dinner with her when she was only young and I went to the other room to inject. When I came back, she had her hands over her ears, so I asked her "what's wrong", she told me, "Dad, when I hear the click, I know you are going to get hurt". Despite me trying to shield her, she could still hear the click of the pen I used to self-administer the Interferon. Seeing my child pained like that brought me to tears.

Stigma

46. You find out soon enough that hepatitis is not something you talk about so you begin to assess the environment you are in and the discussions you can have. There was initially an attitude of ignorance, and then automatically, there is fear. When I started on the Interferon, I was trying to continue my work, but even when you are there you are not really present. There were comments, so I would mention I was having treatment, but never what it was for.

Section 6. Treatment/Care/Support

47. I was never offered counselling and I think it would have been useful for me to have, especially when I was preparing for the transplant. Hepatic carcinoma is something that is constantly on your mind, but when you are actually faced with it, that is very challenging. As a thalassaemic, we did have psychologists on hand at the unit. After the ablation, I saw someone at the McMillan Centre at the Royal Free, but I did not find them helpful. I needed someone more specialised.

Section 7. Financial Assistance

48. I received £25,000 from the Skipton Fund, but I am not sure when.

Section 8. Other Issues

49. The feeling I would like to convey is very simple, it has fundamentally ruined my life. Although I consider myself a strong character, the end result is that even at 60 I had a lot of life to give and a lot of that has been taken from me. What I had to go through caused me to lose a lot of my confidence. I was successful in my business life and I lost that willingness to succeed.

50. When I was young I was in control. I chose whether I wanted to live or die, through my decision to accept treatment. For example, I am a diabetic, if I do not control my diabetes correctly, that is my fault. This is different, I cannot control it. What makes me so angry is I had nothing to do with it, it was that one (or multiple) transfusion with infected blood that completely changed my life.

Statement of Truth

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

Signed GRO-C

Dated 8/01/21