Witness Name: Charles Gore
Statement No.: WITN4530001
Dated: 14 April 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CHARLES GORE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 30 October 2020.

I, Charles Gore, will say as follows: -

1. Charles Gore GRO-C Switzerland. DOB: GRO-C 1957. BA economics/law; CEO The Hepatitis C Trust 2000-2018; President, the European Liver Patients Association 2004-2006; President, the World Hepatitis Alliance 2007-2017; currently Executive Director, Medicines Patent Pool.

2. With three other people also living with hepatitis C, I set up The Hepatitis C Trust in 2000 to provide information and support to others living with hepatitis C. The Trust was initially set up as an unincorporated charity and, while the other three people became the settling trustees, I took on the role of CEO. When we set up the helpline, with the attendant risks of offering advice, we decided that we should incorporate the charity so in 2004 we had to close the

charity and set up an identical incorporated charity to which everything was transferred (at the time this was the only way to do this).

We set it up because all four of us had struggled to find reliable information or proper support. At the time there were over 500 charities registered in the UK dealing with HIV but none for hepatitis C. The Trust was for hepatitis C generally, not specifically for people infected through the NHS. The initial aim was to provide trustworthy information and peer support but within a short period advocacy on behalf of people living with hepatitis C in general also became an important aim. The advocacy centred around making sure that hepatitis C was a priority area for the four countries of the UK, in particular diagnosis and access to the best treatments. Over time and as a result of our work in the international arena persuading the 194 Member States of the World Health Organization, including the UK, to commit to the elimination of viral hepatitis as a public health concern by 2030, the advocacy focus shifted to ensuring that the UK's four countries developed their own elimination plans for hepatitis C.

In, I believe, 2010 the Department of Health asked if I would be willing to be one of three settling trustees of the shortly-to-be-established Caxton Foundation (named after the DH's Caxton House building). I agreed because I thought it might benefit from my own experience of living with hepatitis C and consequent cirrhosis, as well as my experience of taking interferon treatment which, although it cured my hepatitis C, caused an autoimmune response to my pancreas, leaving me with chronic pancreatitis and insulin-dependent type 1 diabetes.

3. Although I was diagnosed with hepatitis C in 1995 my GP gave me the impression it was a very minor infection so I paid no attention. I then became very ill and had cirrhosis diagnosed in 1998, at which point I spent a lot of time researching the subject and found out then about transmission through blood and blood products.

4. In my opinion – and this is only my opinion – very broadly I think in the 1980s and 1990s there was an idea that hepatitis C was a relatively mild disease, partly because of the length of time it takes for its life-threatening consequences to appear, and so there was less experience of that in the medico-scientific community. An example would be my GP who, when I was diagnosed in 1995, did not refer me to a specialist and gave me just one piece of advice for dealing with it, which was “try not to drink too much’. Having said which, I do not think it is possible to talk about the medico-scientific community as if it was homogeneous. Clearly some liver specialists, who were seeing end-stage liver disease consequent on hepatitis C, realised much earlier that it is a dangerous disease and by 2000 I would say this was becoming much more widespread. Since I was not involved before 2000, I cannot comment on whether there was a delayed appreciation of its seriousness by the Government or the Blood Services.

5. The Department of Health (DH) employed an agency to come up with a campaign to raise awareness, called Face It! It involved a series of pictures of people with hepatitis C looking no different from anyone else. I was pleased that the DH wanted to raise awareness and liked the idea of showing that people with hepatitis C look no different from anyone else. However, the implications of the strapline Face it! and even more so of the sub-strapline Face Your Past were highly undesirable and stigmatizing, suggesting that people with hepatitis C had done something wrong that they should now face up to. And, of course, it was supremely inappropriate for people infected through the NHS. This was clearly a case of an agency coming up with something ‘clever’ at the expense of something good and appropriate. We (The Hepatitis C Trust) were increasingly vocal in our criticism and eventually the campaign was dropped and a new one instigated with the strapline Get tested! Get treated! as the new direct acting antivirals became available. Aside from its inappropriateness it was also not sufficiently funded, meaning that it had little impact.

6. All of the campaigns the DH launched after I began working in hepatitis C I believe were aimed at encouraging people who received blood transfusions

prior to 1991 to get tested but none were specifically aimed at them. I do not believe they were sufficiently visible nor were they sufficiently strident, given that they needed to persuade people to stop, think whether they might have had a transfusion and then take action, especially since that transfusion would have been many years in the past. As an example, Dame Anita Roddick, a very well-informed person, was never reached by any of these campaigns and was only diagnosed by chance. I do, however, recognize that DH was given very limited funds and was constrained by not wanting to be alarmist.

7. A) Since I was not involved in the many discussions that took place between 1990 and the introduction of the look-back in 1995, I am not really qualified to comment. What I know is therefore essentially hearsay. However, from an outsider's point of view, a major problem was that it relied on people who had given blood before 1991 again giving blood during the 1991-5 period. Anyone who had hepatitis C and gave blood in the 1970s and 1980s but then stopped donating prior to 1991 would have been missed by the look-back. Since at the same time potentially high risk people were being discouraged from donating (and hence would not be captured and their previous donations traced), inevitably it only found a fraction of the people infected through transfusions. A second big problem is that it focused only on blood donors rather than asking anyone diagnosed with hepatitis C in any setting whether they had donated blood and then tracing those donations. This would have allowed tracing to continue after 1995. One of the 'faces' of the Face it! campaign who I got to know was diagnosed after the end of the look-back. He had photos of each batch of blood he had received after an accident before screening was introduced. He offered them to the NHS but no-one was interested. I can put the Inquiry in touch with him if that would be useful.

   B) Again, my knowledge is hearsay but it appears that a major consideration was that no treatment for hepatitis C was available. This was apparently the 'ethical' argument, which is not ethical at all, merely paternalistic. It is in fact unethical to withhold information from someone when that information could allow them to protect themselves from the sequelae of hepatitis C by for example stopping drinking alcohol and also to protect people they care about from infection.

8. I have no knowledge of any publicity campaigns for the look-back exercise as I was not working in the field then.

9. I was one of the members of the Short-Life Working Group in my role as CEO of the national UK hepatitis C charity. The members agreed on the final recommendations, although (a) I was surprised by the low numbers estimated of people likely to be undiagnosed and living with hepatitis C but I could not fault what I saw of the methodology and (b) I had to agree that some of the options I would have preferred for finding them were simply not cost-effective if those numbers were right, given the UK's threshold for cost-effectiveness. However, if the numbers were wrong or the threshold changed, the conclusion could have been different.

10. I have very little detailed knowledge on the pilot, only that it happened in I think 1991 and 1992 in Scotland and showed that it was feasible.

11. Calculating the likely infectivity rate of HCV in the UK through blood transfusion is extremely difficult and I certainly do not have the expertise to produce reliable estimates. In the article "Too little, too late", when I talked about similar numbers being infected through blood transfusions, I was not meaning exactly the same number. I was talking broadly about thousands. The original paper (Soldan, Ramsay, Robinson et al) that suggested nearly 30,000 is considered a significant overestimate.

12. The DH approached me and asked me, primarily I think as someone with the lived experience of hepatitis C and as CEO of the national hepatitis C charity, to become a settling trustee of the Caxton Foundation, i.e., a trustee involved in its establishment. Once it was established, I held the post for a little over one year. My stepping down coincided fairly closely with incorporating the charity – like The Hepatitis C Trust, the Caxton Foundation was established

as an unincorporated charity but when it was felt that the liability of the trustees should be limited it was incorporated as Caxton Trustee Ltd.

13. The Caxton Foundation was set up after a government review following continued pressure from the affected community. My understanding was that from a government perspective the aim was to stop that pressure. The idea was that, by making payments for those infected with HCV comparable to those for people infected with HIV, a level of 'fairness' would be established that would satisfy the affected community.

    A) I don't believe I made any substantive contribution to the modelling exercise since it was largely a data exercise.

    B) My contributions to this report were primarily around the experience of living with hepatitis C in an attempt to ensure that the overall impact of having hepatitis C was given due weight, including socio-economic effects, not merely its impact on the liver. I also attempted to ensure that people who were infected through blood transfusions were not disadvantaged with respected to people with haemophilia, since I felt my role was to represent everyone infected, not just certain groups.

14. In my role as trustee I had really no interaction with the other Trusts and Schemes. The Caxton Foundation's chair, Peter Stevens, had been a trustee of the Macfarlane Trust and took on the role of managing those relationships. However, I was peripherally involved with the Skipton Fund through The Hepatitis C Trust's helpline which interacted with people wanting advice on their eligibility and help with applying. The Caxton Foundation's National Welfare Committee, of which I was not a member, decided on the applications. If I remember rightly the eligibility criteria were based on being a Skipton Fund recipient (i.e., showing to the Skipton Fund's satisfaction that NHS blood or blood products had been the cause of the hepatitis C infection) and being 'in need', which was a legal requirement for which my input was not required.

15. Yes. When the Skipton Fund was in the process of being established, I raised the issue of establishing the cause of infection and hence the eligibility for payments. Whereas people with haemophilia largely had clear records of their receipt of blood factors, people who had received transfusions would likely have difficulty getting hold of records. Thus, people who had been infected through NHS transfusions might be denied payments just because they could not prove it. When I put this to the DH I was clearly told, unfortunately verbally, not in writing, "we would much rather pay someone who doesn't deserve it than not pay someone who does". But in practice, in my view this is not what happened. I accept that a judgement call was often required and this is public money but in my view the Skipton Fund refused too many applications. A particular case from our helpline sticks in my memory: a woman who had some but not crystal clear evidence of a transfusion was refused a payment because a nurse had written in the application – "drug user". In fact, she had only ever used cannabis, which is therefore irrelevant.

16. A) Firstly of course there is the potential issue of conflict of interest, which may not always be possible to adequately mitigate through recusal from certain decisions, for example. Secondly, there were many groups involved in the infected blood issue, often with conflicting aims. Given the limitations on the number of board seats available, there was the real possibility that some groups would have felt that others had been favoured over them. Additionally, my experience of attending certain meetings of some of the groups made me concerned that board meetings could turn into highly emotionally charged battlefields. There were particularly sharp divisions between some of the haemophiliac groups and some of those infected through transfusions. Finally, if it were possible to find one or two people who could represent the whole range of people infected without being conflicted, it is asking a great deal of people to take on that role. I saw my role as a trustee as trying to do exactly that. I found it very hard and it was one of the reasons that I stepped down after a year. Having said which, I was always convinced of the importance of involving the beneficiaries as much as possible, just not necessarily through seats on the board.

B) I saw my role as trustee as partly being able to provide the insight of someone who had lived with hepatitis C for many years, albeit not a Skipton Fund beneficiary. When I stepped down, I urged the board to appoint someone with the lived experience of hepatitis C to, in some sense, replace me. The Hepatitis C Trust, however, never appointed or recruited anyone.

C) I absolutely felt it was crucial and is the reason I agreed to become a trustee in the first place. As an example, at the board meeting on 4th August 2011, as you will see from the minutes, Prof Howard Thomas gave a presentation to the board about hepatitis C. You will also see that I added to it because Prof Thomas's talk, while very clear, was essentially medical. It really gave no idea what it is like to live with the illness, which is both a liver disease and a systemic one. I believe I was able to highlight some of the socio-economic issues like stigma, energy, employability and mental health that were critical for anyone making payments to infected individuals to grasp.

17. The Caxton Foundation was legally independent of the DH, although of course it was entirely funded by the DH. During my tenure I was not aware of any attempt by the DH to influence the board's decisions. As far as I remember all that was required was a report to the DH on the use of the money, in line with what would be expected of any charity reporting to its funder.

18. The central issue underlying the whole payments issue for those affected by hepatitis C is that it affects people differently. I personally know people who were infected through the NHS, had no symptoms, took treatment when it became available and were cured. It is very questionable whether there was any impact on their lives at all. Equally I know people who were infected through the NHS, had very significant symptoms, were unable to carry on working for so many years that when they were eventually cured it was too late to restart a career, whose relationships broke up under the strain and who were therefore impacted enormously financially, emotionally and in many other ways. When the DH took the decision to have a blanket policy for everyone, inevitably for some people the payments would be too much in

relation to their situation but for others they would be totally inadequate. It therefore goes without saying that people robbed of a lifetime's earnings by hepatitis C could not have that replaced with the sort of funding available to the Caxton Foundation.

19. I believe that certainly the funding issue was raised with the DH, although my memory is sketchy as to how. I think it would have been done through the chair, Peter Stevens. Certainly, I had misgivings once the Foundation started operating. It was clear that some beneficiaries felt they were having to beg for quite small amounts of support when they should have been entitled to very much more. That the scheme was really not achieving what I had hoped led me to step down after the first year. I did not communicate this to DH directly.

20. I don't believe the Caxton Foundation had a "responsibility" to identify beneficiaries but clearly we wanted to do that. There were a number of issues. Those eligible for the Caxton Foundation were those eligible for the Skipton Fund, so the Skipton Fund in practice were responsible for determining eligibility. Firstly there was a problem of contacting those who had received Skipton Fund payments, since data protection meant this could not be done by the Skipton Fund directly unless they were in direct communication with the Skipton Fund (people might have moved, might not wish to be contacted, mail opened by e.g. a new partner might cause huge distress etc). Then there were those who had not applied to the Skipton Fund but were nevertheless eligible.

21. The Caxton Fund made use of the Skipton Fund where it could and the DH contacted clinicians. The Hepatitis C Trust used its helpline to alert people. Unfortunately, the Caxton Foundation did not have the resources to reach out to the general population.

22. I would like to have seen more done because that would have also meant doing more to alert people to get tested in the first place. Since hepatitis C is both life-threatening and completely curable, it is tragic that people may not be tested until they already have liver cancer. Of course, public money is

limited and the cost effectiveness of, for example, a proper national awareness campaign may not be demonstrable, although that depends on how many people infected through the NHS are still alive, which clearly declines every year. By waiting so long to take proper action the government (in fact successive governments) have given themselves a good reason for continuing inaction.

23. A number of means were used to let beneficiaries communicate with the Caxton Foundation to give their views, make comments etc. Forums were planned but I don't think the first one had been held by the time I stood down. The trustees were undoubtedly keen to interact with beneficiaries, though whether we/they did so in a way that fully met the beneficiaries wants or needs is another question.

24. I felt – and I want to stress that this is a personal view not supported by more than hearsay – that, because the Caxton Foundation used the Skipton Fund staff and those staff were there as much to make sure payments were not made to people who could not 'adequately' demonstrate their eligibility as to make payments to those who could, there was perhaps an approach that tended more to caution than to generosity and/or that beneficiaries perceived that. This was perhaps most true at the beginning when processes for the Caxton Foundation were still being put in place. Steps were taken to try to make applications easier and to help beneficiaries with those applications.

25. The eligibility criteria were the same as for the Skipton Fund. This was set by the Skipton Fund. The types of payments were set by the Trustees of the Caxton Foundation, for example debt relief.

26. No since this was done by the Skipton Fund.

27. For the Skipton Fund yes, since a medical opinion was needed as to the most likely route of transmission.

28. As far as I remember, the Caxton Foundation staff were available to help beneficiaries with their applications but I cannot comment on how useful in practice this was.

29. I think it is clear that beneficiaries were not always certain about what they needed to provide. However, inevitably in the early days of an organization making discretionary payments getting this right can be a challenge. In addition, the staff had both a duty to the beneficiaries and to the public purse, which creates a tension between making it as simple as possible to make applications and the need for adequate documentation. I cannot give details as I was not on the National Welfare Committee.

30. I was aware that there were dissatisfactions. Underlying this was often the perception that beneficiaries were being made to jump through ridiculous hoops to get support that they should have received by right. I did my best to put the case with the National Welfare Committee that the application should be streamlined and only the minimum supporting documentation requested. However, the Caxton Foundation had a duty to use public money properly and did not want to cut any corners. The correspondence you cite was from 2014, significantly after I had left the Foundation.

31. The Hepatitis C Trust's main interaction with people affected by hepatitis C is via the helpline. The helpline staff have continued to inform everyone they come into contact with who might be eligible about the trusts and schemes available. In addition to informing people of their existence they also offered advice in how to apply. In addition, The Hepatitis C Trust newsletter and website were used to inform people.

32. Knowledge about the Skipton Fund and the Caxton Foundation and how to impart it and support people is part of the helpline training. If you would like more details, I will need to speak to the Head of Support Services who has managed the helpline since 2003.

33. The relationship between The Hepatitis C Trust and the trusts and schemes was OK but there were cases where we disagreed with their conclusions. I definitely felt that some people who were refused payments were deserving and that there was a marked departure from what DH had originally told me about preferring to pay someone who was not deserving than refuse to pay someone who was. Over time we built a closer relationship with the Skipton Fund and were able to discuss issues with them. Whether or not this helped them become a little less rigid I'm not sure. I would like to think so.

34. After my tenure ended I had very little interaction with the Caxton Foundation partly because I simply did not have the time as, in addition to being CEO of The Hepatitis C Trust, I was also Executive President of the World Hepatitis Alliance. I have no interactions with the trusts and schemes currently as in 2018 I was asked to move to Geneva to run the Medicines Patent Pool, a UN-backed public health organization, partly funded by the UK FCDO, that provides access to affordable medicines in low-and middle-income countries.

35. I'm not really in a position to comment on the running of the Trusts and Schemes aside from the Caxton Foundation during the time I was a trustee. During that time, we were attempting to get it up and running so there were inevitably some teething issues, especially around office space and using staff already working for other Trusts. I do think that the settling trustees, particularly Peter Stevens with his long history and very personal involvement with the Macfarlane Trust, made every effort to ensure the Caxton Foundation was a well-run operation. The feedback from beneficiaries suggested that after the initial period where policies and structure were still being put in place, there was a noticeable improvement in its running.

36. Historically, The Hepatitis C Trust under my leadership was less involved in campaigning on the issue of 'infected blood' than some people thought we should be. We took the strategic decision to concentrate our limited resources on the issue of diagnosing those infected with hepatitis C and ensuring they had access to the best treatments, thereby preventing them dying from liver failure or liver cancer. Nonetheless the Trust was involved in the subject over

many years with the DH, the devolved administrations, the Archer Inquiry and with the affected community. Given that the haemophilia groups were organized and vociferous, the Trust tried to make sure that the voice of those infected through blood transfusions was equally heard.

Statement of Truth

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

Signed GRO-C

Dated 6/5/2021