

Witness Name: Margaret Kennedy

Statement No.: WITN0911001

Exhibits: None

Dated: 10.3.2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARGARET KENNEDY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 8 December 2020. This statement is based on my recollections of events, some of which took place a number of years ago. Whilst I have reviewed the documents that the Inquiry has provided to me, I am relying on my recollection when answering some questions and my recollection is limited in relation to some matters. I have answered the Inquiry's questions to the best of my ability but it is possible that there may be other documents available to the Inquiry which would shed further light or show my recollection to be incomplete.

I, Margaret Kennedy, will say as follows: -

Section 1: Introduction

1. My name is Margaret Kennedy (née Casey) and I was born on GRO-C, 1963. I live with my husband at an address in the GRO-C which is known to the Infected Blood Inquiry.
2. I am a trained podiatrist, and manage a podiatry service provided to the public by a National Health Service (NHS) Trust. I have been employed by the NHS for the past thirty years.
3. I held the position of Trustee of Caxton Foundation (Caxton) and was also asked by the Board to be a member of the Welfare Committee, which I

voluntarily accepted. I was appointed as a Trustee following my application and an interview at Alliance House.

4. My role was to help the charity meet its objectives in terms of providing financial assistance and other benefits to those who have received blood products from the NHS and subsequently become infected with hepatitis. I carried out my role by attending the Board meetings and giving my opinion on discussions.
5. Prior to my first Board meeting I had a 1 hour discussion / induction about Caxton with the person who was Chair at that time. I cannot recall what was covered in my induction or whether it covered Caxton's objectives.
6. I understood the aims and objectives of Caxton to be those according to the Charity Commission website. I think that these were included on the application for the role. I think I remember looking on the Charity Commission website around the time of applying for the role. I have accessed the aims and objectives via the Charity Commission website whilst writing this statement and these were:

“5.1.1 to provide financial assistance and other benefits to meet any charitable need of: a) individuals who have received blood, blood products or tissues from the national health service and in consequence have been infected with the hepatitis C virus; and b) an individual who has been so infected by a person in 5.1.1(a); each of whom has received a stage 1 payment other than excluded persons (together called "primary beneficiaries"); and c) the partners, parents, carers, children and dependants of primary beneficiaries and the partners, parents, carers, children and dependants of primary beneficiaries who have died; and d) the partners, parents, carers, children and dependants of any other individuals who died before 29 August 2003 and whose estates have, for the reasons given in Schedule 5, received a payment under the Skipton Fund Agreement (2); and 5.1.2 to assist the Macfarlane Trust and the Eileen Trust by providing them with accommodation, administrative services and support.”

7. The time I spent carrying out my voluntary unpaid role was initially a day each quarter for Board meetings, then it increased as I joined the Welfare

Committee which met every 6 weeks. Pre reading of information before each Board and Welfare Committee meeting was 2-3 hours and regular emails about urgent requests for financial assistance were reviewed and my opinion given that day.

8. I was not, and have never been, a member of any other committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference.
9. I have not provided evidence to, or been involved in, any other inquiries, investigations or litigation in relation to human immunodeficiency virus ("HIV"), hepatitis B virus ("HBV"), hepatitis C virus ("HVC") infections or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products.

Section 2: The Alliance House Organisations (AHOs)

Appointment of Directors

10. I am unsure of the appointment process for members of the Board of Caxton previous to when I started. The majority of the Board were in their role when I started. When Ann Lloyd resigned as Chair, I was involved in the interview process as an interviewer for the next Chair and another Board member. The applicants were shortlisted from a group of applications put forward by a recruitment company. During my tenure, the composition of the Board changed as some directors resigned and some had their tenure extended due to the forthcoming closure of Caxton.
11. The Board elected directors and we did re-elect directors near the closure of Caxton when it was close to the final date for its existence as it made sense not to have new trustees at such a late stage. I recall that when we offered the positions of Chair and board member they needed approval from the Department of Health. I do not know if the Government was always involved in the process for electing and/or re-electing directors.
12. Regarding the recruitment process for my position, I saw an advert on The Hepatitis C Trust's website about being a Trustee of Caxton. I felt I would be able to make a difference for the benefit of beneficiaries and it would be something positive coming from my hepatitis infection. I therefore applied

and was interviewed by various Board members about my background etc and was appointed. I have experience of living with hepatitis C and with the treatments to eradicate the virus. I understood the discrimination aspect of having hepatitis C and the worry and horrendous side effects of the treatment. I understood the effects of not working due to illness on finances (I was put into care as a child). I come from an extremely poor background, have lived on benefits, GRO-C and have had to request charitable help when I was a student with no public funding for my podiatry course living away from home. So I fully understand the desperation of having to both request funds from a charity and live on a tiny budget below the poverty line. These life skills I felt would balance the Board and allow me to represent those affected by hepatitis C.

13. I do not know how many Directors were appointed by the Government nor by the Haemophilia Society and I was the only Director living with hepatitis C.
14. I do not know specifically how long each Director was on the Board. Directors could be re-elected but I do not know how many times.
15. I do not believe Directors were remunerated for their work. As far as I was aware Directors only received the costs of their travel and, if needed, accommodation. They claimed these back by providing receipts. I do not recall further details of any policies on this.
16. I was not involved with the other Alliance House Organisations however I do know that one Caxton trustee was also a trustee of Skipton.

Structure of the AHOs

17. Caxton shared office staff and a Chief Executive with other Alliance House Organisations. I was aware of strict confidentiality between the organisations as they were separate entities. I understand the Chief Executive managed data sharing and confidentiality issues and I was not aware of information that belonged to the other Alliance House Organisations. The office staff shared offices in Alliance House on the same floor. I only once went into the offices for an introduction briefly so I do not know how confidentiality was maintained or if there was any data sharing. I do not know how documents and information were stored however I was aware that there were paper

documents stored safely in the building. I do not know if data was shared across the AHOs

18. Caxton was already acting as an employer for all five of the Alliance House Organisations before I started and therefore I was not involved in any decisions relating to this. As such, I do not have specific knowledge of the reasons why Caxton acted as employer for all five organisations.
19. I have limited knowledge of the relationship between the different AHOs therefore I am unable to provide the Inquiry with details regarding this. The other AHOs were rarely mentioned to me.
20. I do not remember why the Liaison Committee between the Macfarlane Trust and Caxton ceased except to say that the Liaison Committee meetings were replaced by regular discussion meetings every 4 months.
21. I was not aware of any difficulties between the senior management and the Trustees. I can only comment on my experience of this but it appeared to me to that the trustees had a good working relationship with senior management and that management were open and transparent and everyone acted with integrity and treated each other with respect.
22. I presume Caxton, as a charity, was regulated by the Charity Commission. I say this as we had to produce annual, audited financial statements.

Relationship with Government

23. I recall that Caxton had a relationship with Government but I do not know the extent of how independent it was from Government. I do not know how much involvement the Government had in the composition of the Board as the Board was in place when I started. I recall that when we offered the positions of Chair and board member they needed Government approval so I understand that the Government had some oversight. I presumed this was because funding came from the Government and the Chief Executive reported to the Government. Policies adopted by Caxton were already in place when I started. I presume now that the way Caxton should have discharged its responsibilities to beneficiaries were prescribed by the Government on the setting up of Caxton, however, I do not recall having detailed knowledge about this at the time when I was a Trustee. The kinds of

applications that Caxton should grant were already set out in guidelines and set by precedent applications when I started, however, whenever a new scenario presented itself it was raised at the Welfare Committee and we decided if there was charitable need. I do not know if the Government provided direction or guidance to Caxton in respect of the type of applications that it should grant. The precedents set by new decisions were then used to benchmark future decisions on the same subject. Office Guidelines were changed to reflect this. I was not aware of any limit to the number of grants that could be made except that we had to work within a financial budget for all four devolved countries.

24. I understand that issues about funding were raised by Caxton with the Department of Health before I started. I was aware that the Department of Health had refused an application to run a support scheme. Instead the Board decided to run a scheme to allocate existing funds to those beneficiaries whose income indicated they were below the 70% median poverty line. I believe issues were also raised about the numbers of applicants increasing with no further increase in funding for administration staff however the Department of Health said that the existing resources were adequate. I understand concerns were raised about the effect that a new structure for running all five AHOs would have on existing staff as uncertainty about jobs was a risk to Caxton in terms of staff then looking for other jobs and possibly leaving. As far as I was aware the Government did not respond to this.
25. I'm not aware that Caxton had any contact with DWP. As far as I was aware the DWP did not take into consideration grants or funds allocated by Caxton when assessing whether somebody should receive benefits. I was not aware of any beneficiaries having their DWP benefits stopped as a result of assistance they received from the AHOs.
26. I was aware that Caxton's Chief Executive was a point of contact for the Department of Health however the point of contact at the Department of Health changed according to General Election results, restructuring of the Department of Health and redundancies and retirements amongst the staff in the Department of Health. I did not attend meetings between Caxton and the Department of Health so I was not aware if there were any difficulties.

However, I was aware that whenever there was a change of staff at the Department of Health then the Chief Executive and Chair of Caxton wrote to whoever they were reporting to at the Department of Health to introduce themselves and Caxton. I presume that each time there was a change in who was the point of contact at the Department of Health then the new point of contact would not have historical knowledge of Caxton so this would need explaining.

Section 3: Funding/finances of the AHOs

27. Caxton received funding from the Department of Health. This changed over time as the Scottish Government decided to manage the funds themselves as did the Welsh Government and Northern Irish Government closed the funds. I was not aware of any problems with this as the remaining funds were in place for England. When Caxton was dissolved the residual funds went to the NHS Business Services Authority (BSA).
28. I do not know about how the initial funding budget for Caxton was set by the Government as this was before I started. I was not involved and I cannot comment on what input Caxton had in this as that is outside of my knowledge. I do not know if the Government took account of representations made by Caxton.
29. The only information I was aware of about the beneficiary population was that they had received a Skipton Fund grant. I do not know what information Caxton had generally about the beneficiary population or what Caxton felt it needed to have to meet beneficiaries' needs. I do not know where Caxton received its information about the beneficiary population from and I do not know what information it provided to the Government.
30. I think that the funding allocated to Caxton by the Government was adequate. I say this because I recall that we did not need to refuse any grants because of a lack of funding.
31. If we were close to reaching the limit of the allocation from, for example Wales, for funding grants then the Chief Executive would write to the devolved Department of Health and ask for an increase in allocations. I know that extra funds were allocated for Northern Ireland

32. I was aware of annual reviews between Caxton and the Department of Health where Caxton's Chief Executive attended. I think these were in meetings. I do not know who set the agenda, who else attended, if minutes were taken or what was discussed. I think the Chief Executive could take board meetings along to the meetings which would have recorded discussions other directors who were not attending had previously had.
33. There were also other instances where the Chief Executive met with Department of Health officials and there were occasions where the Chair of the Trustees met with Department of Health officials. I was not present at these meetings so I cannot provide the Inquiry with further details about them.
34. I was not aware of any other forms of income or funding that Caxton had during my tenure, other than that provided by Government.

Financial management / governance

35. Budget forecasts were made by Caxton prior to the financial year based on the income expected to be given by the Department of Health for that year. The budget was decided before I started and so the needs of the beneficiaries were determined then. It was reassessed each year but beneficiary needs were forecast before I started. I do not know how as I was not involved. Whilst I was there however certain parts of the budget were moved around. I was aware of the budget allocated for the welfare grants and for the regular payments scheme. The forecast for the budget for the regular payments scheme was within our existing budget.
36. Initially, when there was a spike in applications for assistance, the Board asked for more funding however this was refused by the Department of Health. I understand this was because the Department of Health thought that the applications could still be dealt with within the existing budget, despite the increase in the number of applications. At times, the funding Caxton had been allocated for certain devolved countries was close to being used up so Caxton made further applications to the relevant devolved county's Department of Health or equivalent for more funds and as far as I recall received these.

37. I understood that Caxton could not have reserves. I was not involved in decisions about reserves (that had been the position since before I started).
38. I was not aware of any impact the level of reserves had on Caxton's negotiations with the Government for increased funding.
39. I cannot recall any cuts Caxton made to its operational costs to maximise the monies available for beneficiaries.
40. The Inquiry has referred to minutes of a board meeting that took place on 9 November 2016 [CAXT0000094_141] which note that the AHOs engaged a specialist company to assist with their bid to be the new scheme provider at a cost of £8,625. The Inquiry has asked how this was funded and whether it was considered that this was a good use of Caxton's funds. I presumed this was funded through the budget for Caxton. As far as I am aware, CF decided this was a good use of public funds as it was felt that the bid by Caxton to be the new scheme provider was the best way to support the beneficiaries as current staff of Caxton had historical knowledge and skills regarding beneficiaries. In order help ensure that the bid would be effective and successful, Caxton felt that external support to put the bid together was needed.
41. I understood that the pay for the Chief Executive was in line with other Chief Executives in the charitable sector at that time on a like for like basis. I understood that before I started at Caxton there was a review of staff and that salaries were based on job descriptions from this review.
42. The Inquiry refers to a meeting of 9 November 2016 [CAXT0000094_141] where it is noted that staff would be paid an additional three months remuneration and the redundancy policy was to be amended. The staff were to be paid this additional remuneration as it was felt that otherwise there was a risk that the staff could leave due to job uncertainties. If staff left then the function of aiding beneficiaries by Caxton would have been at risk.
43. I believe Caxton's finances were generally well managed whilst I was there. However, I recall an instance where the Chief Executive made the Board aware of an issue regarding an intercompany transfer. I recall that the Finance Director at the time made a fundamental mistake. I think the mistake involved transferring money from one organisation to another without having the correct authority from two people, which could have affected the audit at

the end of the year. The Chief Executive mitigated any risks and kept the Board informed as to how to prevent this happening again going forward. There was no loss to charity as the mistake was noticed and the money was transferred effectively.

44. I believe Caxton underspend on its grants budget for 2015/16 due to there being a generous budget set at the start of the year due to Caxton believing that the increase in beneficiary numbers would increase the number of applications. I believe there was an increase in applications but not a huge increase in the cost of the applications, which meant Caxton underspent on its grants budget for that year.

Section 4: Your role as a Director with experience of living with HCV

45. I cannot recall being a registrant with Caxton.
46. The other Directors treated me with respect at all times. The advantages of me being a director were that the voice of someone living with hepatitis C was heard when the Board was making decisions about the beneficiaries. I did not perceive that there were any disadvantages.
47. I felt that my views about matters relating to Caxton, including about payment types and awards of grants, were adequately taken into consideration at Board meetings as each Board member was listened to and discussions were thought through and fair. We did not always agree on decisions but each voice was heard and a consensus reached.
48. I do not recall that there were any decisions that I was unable to participate in due to a conflict of interest.
49. The Inquiry asks whether I consider that I was able to adequately represent the interests of the beneficiaries. I have explained in paragraph 10 above why I considered that I was a good addition to the Board in this respect. I think I had life experience that helped to balance out the Board. I could provide views from the perspective of someone living with hepatitis C, which I consider allowed me to represent the interests of beneficiaries.

Section 5: Identifying beneficiaries for the AHOs

50. Beneficiaries applied to Caxton for support themselves. My recollection is that I was under the impression that it was the role of the Chief Executive and Director of Operations to make possible future beneficiaries aware of the existence of Caxton and what it could offer in terms of support.
51. The Inquiry asks how potential beneficiaries were identified. There was a lookback exercise before I started which was carried out by Skipton. This involved Skipton writing to or emailing all Skipton applicants to communicate with them about the existence of Caxton and how it could help them. There was also a website that potential applicants could visit for further information. I do not have any further knowledge of how Caxton beneficiaries were identified. I remember we tried to increase knowledge about Caxton by putting information on Caxton's website.
52. The Inquiry asks what steps, if any, were taken by Caxton to advertise its existence and/or raise awareness of its work. Caxton had a website and updated this frequently and there were regular newsletters sent to beneficiaries updating them on how they could be helped and providing an update on the latest news concerning Caxton, amongst other things.
53. I was not surprised by the finding that many people infected with hepatitis C had never heard of Caxton. I was not aware of Caxton until I applied for the Trustee post. My Consultant mentioned Skipton but said he did not know much about Skipton at all himself so I Googled it and found out information myself. In terms of any steps that Caxton took to raise awareness in response to the finding that many people had never heard of Caxton, I recall we discussed marketing at one of my early Board meetings and at various other meetings we discussed updating the website and newsletters. The website was updated regularly and newsletters were sent out every few months to all beneficiaries.
54. The Inquiry refers to board minutes from 13 May 2015 [CAXT0000111_038] which record that the beneficiary numbers increased by 57% between 1 April 2014 and 31 March 2015. From what I recall, it was the increase in awareness that the APPG survey generated that had increased the number of beneficiaries. Caxton absorbed all the extra work and increase in beneficiary numbers within existing resources. Later, extra resources were asked for but were refused by the Government.

55. I do not believe that I considered that any more could have been done to increase the number of beneficiaries or reach out to people who might have been eligible for assistance otherwise I would have brought this to the attention of the Board.

Section 6: Eligibility for the Caxton Foundation

56. The eligibility requirements were already in place when I started volunteering for Caxton. I do not know who was responsible for setting the eligibility requirements.
57. There were some guidelines available on Caxton's website but I cannot recall if these set out eligibility requirements. Having looked at the Charity Commission website whilst drafting this statement, it looks like the eligibility requirements were set out in Caxton's trust deed.
58. My role did not involve assessing whether an applicant was eligible to be accepted as a beneficiary. My involvement was only in matters after someone had been accepted as a beneficiary.
59. It is my understanding that in order to register as a primary beneficiary of Caxton it was necessary to be registered with Skipton. I cannot recall if there were any other eligibility requirements for primary beneficiaries.
60. I cannot recall any eligibility requirements changing whilst I was on the Board.
61. I cannot recall the eligibility requirements for partners, carers and the bereaved. I do recall that we discussed at a NWC meeting the eligibility requirements for children in terms of their age i.e. they are a child until the age of 18 unless they are in full time education in which case they are a child to the age of 21. Otherwise they are classed as an adult in their own right. Support was available to partners, children, carers and the bereaved. Caxton supported non-primary beneficiaries in terms of grants for clothing, furniture, respite breaks, moving house, funerals and headstones, debts, counselling etc as well as support for debt management and support for benefits tribunals and challenging benefit decisions.
62. I felt that the support available for children and carers was adequate in that children over the age of 18 were supported with grants for their further

education and careers. Carers were supported with one off grants and respite breaks.

63. I did not know what the eligibility requirements for the other Alliance House Organisations were. I do not know whether there were discrepancies or differences in the eligibility requirements between the different AHOs.
64. I understand medical evidence was required to determine eligibility however I do not know who was involved in this nor exactly what evidence was asked for except that I presumed applicants were required to show they had an infection of hepatitis C. I do not know how applicants were alerted to the requirements for medical evidence.
65. The Board set the procedural requirements that an applicant needed to satisfy to receive a grant from the Welfare Committee on the advice of the Chief Executive and Director of Operations.
66. I cannot recall why a beneficiary needed to complete a census form. I think this was to collect information about their income but I do not have any further knowledge and do not recall seeing the census form.
67. Caxton introduced a grant application form to reduce the number of stages that would require completion during the registration and grant application process. In my opinion, this helped to streamline the process.
68. I do not know whether there were discrepancies or differences in the procedural criteria between the different AHOs.
69. I do not know if the procedural requirements were written down, available publicly or if they could be accessed by individuals.
70. I was aware that some beneficiaries mentioned that having to fill out forms to provide details of their income made them concerned, however, we were a charity and charitable need had to be shown before we approved any grants. Income was taken into consideration when assessing for charitable need. I presumed the Board highlighted this on the website and if any applications were refused this was explained to the applicant in a letter.

Section 7: Decisions on substantive applications with the Caxton Foundation

The process

71. The office team, which I understand was made up of staff employed by Caxton, made decisions on applications for Caxton where an application could be assessed using the Office Guidelines. I do not know specifically which members of staff carried out this role however I assumed it was the welfare assistants along with the Director of Operations and the Chief Executive. The Welfare Committee was a committee formed to consider and determine applications that could not be assessed using the Office Guidelines. At Welfare Committee meetings we discussed the Office Guidelines for cases so that more cases could be delegated to the office team in order to speed up the process for awarding grants. This meant that only cases that were exceptional or involved new circumstances, and would therefore set a new precedent, came to the Welfare Committee. The Welfare Committee met every 6 weeks and I volunteered to be on this committee not long after I started. The Welfare Committee was already formed when I started and I do not have knowledge of details as to how it was formed or why certain Board members were on that Committee. The Welfare Committee reported to the Board of Directors. The Chief Executive and Director of Operations would attend Welfare Committee meetings as well as other Board members. Prior to a Welfare Committee meeting, papers detailing each application to be considered at the upcoming meeting were sent to those who would be attending the Welfare Committee meetings through the post and we were required to read them before each meeting. At the meetings we made a collective decision on each application. As part of the decision making process, we had to assess whether an applicant had a charitable need. In an emergency the Chief Executive could make decisions on applications and later present these to the Welfare Committee and if any decisions at the Welfare Committee were appealed then these were brought to the attention of the Board. I noted that certain applications where applicants had exceptional circumstances or exceptional histories were brought to the attention of the Board for their opinion as to whether their applications could progress further. This very rarely happened.
72. A 'round robin' was used when it was felt by the office team that a grant application was urgent and could not wait until the next Welfare Committee meeting. These applications were circulated by email to the members of the

Welfare Committee and the Welfare Committee would make decisions on that application by email. We would reply as soon as possible, usually the same day. 'Round robin' applications were given the same level of consideration as applications that were considered during Welfare Committee meetings. The authority to make decisions on round robins was by consensus, we would all agree or not agree.

73. There was a written policy for the determination of applications in the Office Guidelines which were updated whenever there was a need to update them, for example, if there were increases in prices of white goods or to update the guidance on the age of 'child'. Updates to the Office Guidelines were presented to the Board for ratification by the Chief Executive. I cannot recall if the Office Guidelines were publicly available. I cannot recall seeing any other written policies around determining applications however I understood that there was a retrospective policy on applications. I do not know whether expert advice was sought to inform policies nor if the views of the beneficiary community were taken into account when setting the policies. The Inquiry has a copy of the Office Guidelines. I cannot describe any other policies as I cannot recall seeing them.
74. When amending the Office Guidelines a paper would be presented to the Welfare Committee and the Welfare Committee would consider the information. I cannot remember details of what would be in the paper. If agreed, amendments would be adopted going forward. An explanation as to why an amendment would speed up the delivery of grants would be given. Caxton aimed to be as fast as it could in turning around applications for grants. Delegating applications to the office where they could so that they could be turned around fastest would help the beneficiaries the most therefore it was important to update the Office Guidelines as the office could only assess applications that were covered by the Office Guidelines.
75. I was aware that applicants had to demonstrate charitable need when making an application for a grant by filling out an application form. The Board set this requirement. We could only rely on the information that the applicant disclosed. We had no powers to investigate or check the veracity of the application in terms of income and expenditure. The applicants had to submit quotes from at least two providers for any services or equipment in relation

to which they applied for a grant. If housing adaptations were made then we would need to see that the applicant had first tried to access funding via their Local Authority and that there had been a refusal. Or, for example, if a boiler needed replacing then some people could be eligible for funding assistance from, for example, Greenfund and other energy companies that provide boilers for free if you have limited income. Alternative help was suggested occasionally where appropriate. Some beneficiaries did not understand the requirements in relation to retrospective applications for grants so were granted their application but were advised that next time they would need to send in an application before applying for something as it was difficult to demonstrate charitable need if they had paid for an item upfront before asking for help. I cannot recall whether the procedural requirements were reviewed.

76. The Inquiry has asked me to consider minutes of an NWC meeting on 9 July 2015 [CAXT0000042_001] where it was agreed that assistance for baby items for a primary beneficiary would be available after receiving evidence from a medical professional that the mother was at least 30 weeks into the pregnancy. I cannot recall why this evidence was required.
77. I am unsure what exact proportion of grants were approved or not approved, however, I recall that this information was brought to the attention of the Board at each Board meeting.
78. The reasons for refusing an application were that charitable need was not demonstrated and I believe that this was written down and communicated to each applicant.
79. There was a procedure in place to consider applications made on an urgent basis. I understand that urgent applications would be considered by the Chief Executive and often the Chair of the Welfare Committee. The Welfare Committee was notified of urgent applications at each Welfare Committee meeting.
80. I understood the welfare assistants helped applicants fill out the forms if assistance was requested.
81. Regular payments were made to beneficiaries if they met the assessment criteria of having an income below the 70% median. Lump sum payments were made to all beneficiaries for winter fuel allowance. Specific grants were

- made for specific expenses such as travel to hospital appointments. These were paid on receipt of travel expense documents.
82. Each application was considered on its merits irrespective of the overall demand on the fund.
83. The level of payments through Office Guidelines was set before I started and was amended during the time I was on the Welfare Committee. I do not know how the levels were originally set. I think different payment levels were set in the Office Guidelines depending on changes in consumer prices for example for white goods. The board or the Welfare Committee decided whether there should be any increases (I cannot specifically remember who). The regular payments were agreed by the Board as being set to bring up beneficiaries' income to the level of the 70% median for income.
84. I do not recall if Caxton considered previous amounts of money given to applicants when determining applications.
85. I was aware that there was a significant increase in beneficiaries during 2014 which meant there was the potential for Caxton not to have sufficient existing funds to be able to fund the original amount of £500 for winter fuel allowance. The Board discussed this and decided to allocate a reduced winter fuel allowance. The level of reduction was £150.00 per beneficiary per year. Additional payments could be made if a beneficiary applied for a grant or if funds allowed this later in the financial year. This was communicated to beneficiaries by letter and on Caxton's website. The Chief Executive approached the Department of Health for further funds and these were refused due to the Department of Health feeling that winter fuel payments could be managed with existing funds.
86. I cannot recall how, in each individual case, Caxton took into account Skipton payments when assessing grant applications. However, I recall one occasion where a beneficiary had just received a Skipton grant and the request for debt assistance was refused because it was so close to them receiving the grant and charitable need was not justified as there were funds to meet the debt.
87. I cannot recall why Caxton made the decision in December 2016 not to award grants to those beneficiaries in Scotland who had received the stage

2 Skipton grant unless the grant was to clear debts. I cannot recall whether or how this decision was communicated to beneficiaries.

88. My opinion on fairness of decision making by Caxton when assessing applications was that the decision making was fair and consistent. We reminded ourselves of previous decisions when assessing complex cases to ensure consistency.

Regular Payments Scheme

89. Caxton introduced a regular payments scheme so that maximum use of the available funds could be distributed to those in most need, i.e. those below the 70% median income. Caxton introduced this scheme during the 2014/15 financial year by way of giving beneficiaries that met the criteria a lump sum in March 2015. The funds were then carried forward into the next financial year and given each month i.e spread out over 12 months. Caxton publicised this by writing to all beneficiaries about this scheme. Beneficiaries could then apply under the scheme if they felt they met the criteria.
90. I cannot recall any other attempts by Caxton to secure funding from the Department of Health for funding a regular payments scheme after the business case was declined.
91. I cannot recall why the regular payments scheme took into account Skipton stage 2 payments in the calculation of household income.
92. The regular payments scheme lifted beneficiaries to above the poverty line. This was ensured by giving an extra £750 lump sum to those who had received a payment but who did not get above the poverty line after taking into account their income.
93. The Inquiry asks whether, if after receiving a lower than predicted rate of applications for the regular payment scheme, any other communication avenues were used to raised awareness of the scheme with beneficiaries who may have been living below the poverty line. Two letters were sent to all potential beneficiaries advising them of the new regular payments scheme. I am not aware of any other communications that were sent out to raise awareness of the scheme. I presumed the scheme would have been

highlighted on Caxton's website, however, I did not look at the website to see if this was the case so I do not know for sure.

94. An applicant's levels of savings would be taken into account if it was felt they were substantial enough to reason that there was no charitable need. For example, one applicant was refused financial help due to having £266,876.00 savings in the bank (NWC meeting 12 August 2015 [CAXT0000044_003]). I think it was reasonable for Caxton to take this into account in that case.

Loans policy and debt support

95. I think I remember being present at a meeting where it was decided that Caxton could not issue loans to beneficiaries because it was difficult to demonstrate charitable need for a loan. I cannot recall what meeting this was or the exact issues that were discussed.
96. I do not know what the selection process was for appointing Jayne Bellis and Neil Bateman. They were already engaged by Caxton when I started therefore I was not involved with any decisions relating to appointing them. I did not have specific knowledge of what terms they were engaged on. I do not know what information was given to the advisors about beneficiaries nor if the beneficiaries consented to this information being passed on. I do not know the terms on which the advisors were hired so cannot comment on what they were expected to feedback to Caxton. I did not see any reports sent back to Caxton by the advisors. I cannot comment on whether any confidential information that was given by the beneficiaries to the advisors was shared by the advisors with Caxton nor if consent would have been sought from the beneficiaries if it was.
97. I cannot recall why changes were made to Office Guidelines around October 2015 in respect of the wording on debt and mortgage assistance.

Non-financial Support

98. Non-financial support for beneficiaries was available in terms of debt management and benefits advice. I cannot recall if the availability of this support was made known to beneficiaries.
99. Counselling was available to beneficiaries through a separate grants process. Many beneficiaries applied for funding for counselling which I believe was granted in the majority of cases. Cases where this was not awarded would have had extenuating circumstances. Each case was assessed on a case by case basis.

Section 8: Complaints and appeals

100. There was an appeal procedure for Caxton however I cannot recall the details of how this operated. I recall that if an applicant who had made an application for a grant was not happy with the outcome of their application then they could appeal. The same staff who made the original decision on the application also reviewed the appeal however exceptional cases were brought to the attention of the Board. I am unsure if there was the right to give evidence or make representations in respect of an appeal in person. During my time at Caxton, that never happened. It follows that I do not know whether, if an applicant could appeal in person, a representative was allowed to accompany them. I cannot recall what standard of review was to be applied for appeals. Appeals were determined at the following Welfare Committee to take place after the appeal would have been sent to Caxton. It would depend on who was available to attend that meeting as to who heard the appeal. The original decision makers would more often than not be present at the appeal. Written decisions were provided and I was not aware of any time limits or fees for the bringing of a review or appeal.
101. It was not common for appeals to be launched. During my tenure I was aware of only 11 appeals. Of these 11, two appeals succeeded.
102. I cannot recall a complaints process only that there was an appeal process which I took to be a form of complaints process. Appeals were brought to the Welfare Committee and discussed and either overturned or remained the same.

103. As I cannot recall a complaints procedure, I cannot comment on how many complaints were made or how frequently they were upheld.
104. I do not know what information was given to beneficiaries around the complaints or appeal procedure.

Section 9: Engagement with the beneficiary community

105. Caxton sent regular newsletters out to its beneficiaries and had Partnership Group meetings with beneficiaries. Caxton updated their website regularly with information. Audits around communication were also used to gain information on how the beneficiaries wanted to engage with Caxton.
106. The Inquiry refers to Board minutes from 26 February 2014 [CAXT0000110_107] which discuss the reputation of Caxton and the need for a constructive PR campaign. The Inquiry has asked if the Board took any action to improve the reputation of Caxton. The Board did not agree to a PR campaign around that time however I cannot recall the rationale behind this. I recall that these matters were addressed in my first and second meetings with the Board. I cannot recall if the Board took action to improve Caxton's reputation around that time.
107. The purpose of the Partnership Group was to engage with beneficiaries to gain their insight and listen to their concerns. It did this by sharing information with beneficiaries about what Caxton did and planned to do. The Partnership Group could also answer any queries raised by the beneficiaries. I cannot recall how often the Partnership Group meetings took place but it was intended for them to be frequent. The Chair of the Partnership Group formulated the agenda. From what I can recollect, beneficiaries could raise agenda items before the meeting but my recollection regarding this is hazy. The beneficiaries were selected from all beneficiaries not just the campaign groups. A letter was sent to all beneficiaries asking for an expression of interest in attending the Partnership Group meetings and from these the attendees were selected. I believe that these meetings had an impact on the way Caxton operated as I believe they influenced changes in processes by prompting Caxton to reflect on the concerns raised and to give information when requested. I only attended part of one meeting (due to family issues

that day, I needed to leave the meeting early to get back home). I left that meeting with an impression that it ran without any problems. I do not know if any problems were encountered after I left.

108. The previous group was not felt to represent the whole beneficiary community so letters were written to all beneficiaries asking for expressions of interest to attend this group.
109. I cannot recall why the Partnership Group did not meet in the spring of 2015. It is my understanding that Partnership meetings were intended to be more frequent than they actually were. The Department of Health wanted to restructure the AHOs and the meetings came to an end.
110. In my opinion the relationship between the Board and the beneficiary community was one of mutual respect.
111. The relationship between the management/ Board and the campaign groups was not something I was involved in or had much awareness about except when I went to the Partnership Group meeting in November 2014, where my experience was that each campaign group treated Board members with respect and vice versa. Some campaign members were more assertive than others however that is to be expected as campaigners were there for their members to be heard and I understand they lacked trust in organisations. I cannot recall why the Board felt it would be inappropriate to put contact details of the campaign groups in the newsletter.

Section 10: Relationships with other organisations

112. I do not recall being aware of any relationships that Caxton had with the Haemophilia Society.
113. I do not recall Caxton having a working relationship with the Haemophilia Society. I do not recall being aware of difficulties between Caxton and the Haemophilia Society however having reviewed some minutes when preparing this witness statement for the Inquiry I can see that that there was an issue of defamation with a Carol from the Haemophilia Society and the Chief Executive of Caxton which was being pursued legally and that meetings between them could not continue. I am not aware of whether this impacted on the running of Caxton.

- 114. During the time I held my role as Trustee at Caxton, I was not aware of any Directors who were also trustees of the Haemophilia Society.
- 115. I do not recall being aware of any involvement Caxton had with the UK Haemophilia Centre Directors Organisation.
- 116. Given that I do not recall Caxton having a working relationship with the UK Haemophilia Centre Directors Organisation, I was not aware of any difficulties that may have existed between the two organisations.

Section 11: Reform of the Caxton Foundation

- 117. I was involved in the reform of the scheme in that I was informed of what was happening and any actions from the Department of Health.
- 118. The purpose of the Department of Health Reference Group was to act as a sounding board following the end of the Department of Health consultation on the Alliance House entities going forward. I was a member of the Reference Group but cannot recall the full composition of this group. I was not given a list of names. The group included the Chief Executive from Caxton and the Chair of Caxton along with a member from the Terence Higgins Trust and one member from the Haemophilia Society (and others I have forgotten). The group made suggestions, however, I do not know if these influenced decisions regarding the development of the new scheme. I only attended one meeting due to them all being cancelled.
- 119. Regarding the 2016/2017 reforms, the Board had concerns that going forward the beneficiaries may not receive the high quality of interaction they received from Caxton. Caxton staff had historical knowledge of the beneficiaries and understood their concerns so it was felt that Caxton would have delivered a more effective service for beneficiaries.
- 120. I do not recall whether the Department of Health addressed the issues raised in the joint response sent by the Alliance House Organisations.
- 121. I did not raise any objections to any changes suggested nor did I request additional time to consider the impact the changes might have.
- 122. My role in the development of the Special Category Mechanism (SCM) was to give my opinion on this mechanism from a beneficiary's point of view as a director of Caxton.

123. The Inquiry refers to minutes from 10 August 2016 [CAXT0000094_135] which record that I suggested the involvement of a mental health practitioner to advise the Department of Health on the criteria for the SCM. This was raised at a Department of Health Reference Group where the Chair was someone from the Department of Health. The SCM mentioned physical health and I felt that the mental health impacts of hepatitis C should be considered under the SCM as well. I felt that it could have been useful to have input from a professional in this area. I do not know the outcome of this as no further meetings were held and as I do not need to apply for this I am not aware if this became included.
124. I cannot recall the exact details of the SCM eligibility criteria however I recall thinking that I felt like it may be difficult for potential beneficiaries to prove their health had deteriorated as some health issues cannot be measured by blood tests or scans, certainly not mental health issues. The burden of proof would lie with the beneficiaries asking their GPs or Consultants for a medical opinion, and a difficulty is that medical science is not an exact science.
125. The Inquiry refers to minutes of the board meeting on 15 February 2017 [CAXT0000094_145] that note that progress on the SCM had been slow because the criteria for this were being driven by DH's attempt to counter the legal challenges. I do not know what was meant by this.
126. I cannot comment on the relationship between Caxton and the Department of Health during the transition period as I was not at any meetings during that period except the one Reference Group meeting.
127. Regarding the transfer to the new schemes, I was aware that a new data controller would pass information to Skipton with Skipton holding a small amount of money to enable any requests for the data from the public inquiry in the future to be accessed from archives. I was aware that one of the Board members was concerned about the liability of existing Board members for this data and resigned. However, the Chief Executive assured the Board that, following legal advice, current Board members would not be liable for controlling the data for future requests for the data. I do not know what the beneficiaries were told however in a Board meeting we were told that explicit consent was gained.

128. The Inquiry refers to board minutes from 11 November 2015 [CAXT0000094_147] which note that the measure of success for the new scheme would be that “the most vulnerable people we support had been moved over to a new enhanced scheme successfully, without anyone falling through the net” and asks if I believe that was achieved. I do not know whether this was achieved or about the success or otherwise of the new scheme.
129. The Inquiry has referred to minutes of a board meeting on 17 January 2018 [CAXT0000094_039] which note that the Alliance House Organisations would continue to dissuade the Department of Health from advising beneficiaries that they would not be able to make Subject Access Requests to get copies of their files once the Alliance House Organisations closed. I agreed at the time that this was appropriate simply because there were not enough administrators to process a huge number of Subject Access Requests. However, on reflection, I do not think we should have discouraged Subject Access Requests as they would have reassured beneficiaries that Caxton was not hiding anything.

Section 12: Other

130. I consider that Caxton was well run and achieved its objectives. I did not perceive any difficulties or shortcomings in the way Caxton operated or in its dealings with beneficiaries and applicants for assistance.
131. I was a beneficiary from Skipton in my application for funding. I applied later to the EIBSS for the regular payment scheme and winter fuel payment.

Statement of Truth

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

Signed mkennedy

Dated 10.3.2021