

Witness Name: Sue Phipps  
Statement No: WITN4682001  
Dated: 26 January 2021

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF SUE PHIPPS

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

I, Sue Phipps, have approached the task by setting out my current knowledge and will say as follows: -

#### **Section 1: Introduction**

1. My name is Sue Phipps.  
My address and date of birth are known to the Inquiry.  
I have no relevant professional qualifications.
2. I worked in publishing before moving on to focus on voluntary work. My roles involved maximising the profitability of titles by making sure the editorial was aimed at the appropriate target market and the advertisers responded to the opportunity to reach that target market. I was in charge of between 10 and 55 people at different times. I wrote business plans, launch documents, presentations. Skills involved were the ability to communicate ideas, to motivate staff, to manage staff, and numeracy.

From 1977-1991 I worked in consumer and women's magazine publishing, mostly for Reed International.

From 1991-1995 I was a freelance publisher, on a number of consumer titles. I also worked with *The Wellcome Foundation* in the area of communication and PR for Positive Action which is a programme created in 1992 to support communities affected by HIV and AIDS and to help combat stigma and discrimination

From 1996-2000 I was Publishing Director at *Sainsbury's Magazine*.

From 1993-2017 I was a trustee of the Eileen Trust

From 2001- 2005 I worked at Romsey Publishing as Publishing Director on *The English Garden*.

2003 – Present day. I volunteer for the National Garden Scheme, (a charity that gives away about £3 million to nursing and healthcare charities). Since 2010 I have been a Trustee of the NGS and I am currently Deputy Chairman.

3. Apart from being an ET Trustee, I haven't been on any ET committees, working parties or groups. I was invited to become an ET trustee after I put my name forward as someone willing to give time to a Public Appointment and applied via a Government application form. I believe that I had the relevant skills because of my background in marketing and having worked with communities affected by HIV and AIDS. It was, and remains, an issue that I care about. It is hard to remember now what an enormous amount of prejudice and misinformation there was about HIV and how little the average person really understood about transmission etc. We had registrants in the ET who were not prepared to ask for help because they were frightened of the prejudice that they would encounter if they admitted they were HIV positive. As well as the fear of the virus itself they also had to face the overwhelming prejudice of the average man or woman in the street. I worked with a man who was HIV positive and subsequently died of AIDS. He did have close and supportive friends so in a way he was lucky but there were many, many people who didn't have that support.
4. As a Trustee of the ET I was responsible, together with my fellow Trustees, for fulfilling the objectives of the ET as set out in the Trust Deed. These

objectives were to “relieve those qualifying persons who are in need of assistance or the needy dependents of qualifying persons who have died”. In fulfilling this objective the ET provided financial support, amongst other things.

5. I don't remember receiving any formal training or induction. It is possible that I was given documentation at the time but I do not recall whether this was the case and I have not kept any copies. I was also made aware of the objectives and powers of the ET. I became a Trustee 28 years ago and therefore my recollection of this, and certainly the earlier periods of my involvement with the ET, are not perfect and are principally based on those documents which have been provided to me.
6. My only relevant responsibility was as trustee of the ET and member of the board. Before the board meetings I would read the board papers. At the meetings we would, at least since 2002, conduct a case by case review to assess needs. The board also approved grant applications and dealt with urgent requests for grants that fell outside the ET staff remit (ET staff dealt with grant applications that fell within limits fixed by the trustees – approximately 60% of applications). There were three board meetings per annum and sometimes, between board meetings there were telephone conversations or occasionally meetings relating to Trust affairs. In the latter years I went to a number of the occasions where Eileen Trust Registrants came together. In general I would devote about half a day per month to the role.
7. I have no membership, past or present of any body relevant to the Inquiry's Terms of Reference
8. I have not provided evidence to or been involved in any other inquiries etc as outlined in Question 8.

## **Section 2: Establishment of the Trusts and Schemes**

9. I was not involved with the establishment of the ET and have no recollection of the circumstances which lead to it being created. I should add that my involvement with the Trust itself was now some time ago and in writing this statement I have relied heavily on the minutes of the Trust's Board Minutes to refresh my memory in respect of those questions which I am able to answer.
10. My understanding was that the Eileen Trust was a discretionary grant making Trust, set up and funded by the Department of Health ("DOH") to alleviate the financial need of qualifying non-haemophiliac individuals infected with HIV through treatment with NHS blood or blood products and to relieve the needs of dependents of qualifying persons (including qualifying persons who had died.
11. The Eileen Trust was regulated by the Charity Commission
12. The Eileen Trust was set up by the DOH. I was not involved in the process (see question 9).

## **Section 3: The AHOs**

### **Appointments of Trustees**

13. I don't think I can add anything to that which is stated in the 'Appointments Protocol of the Macfarlane Trust and Eileen Trust' [EILN0000009\_099] other than to say that all appointments were in the gift of the Secretary of State. Trustees were appointed for a 3 year tenure which could be renewed and always was. The DOH were sometimes slow to do the paperwork for renewals of tenure.
14. As stated in the minutes of 16<sup>th</sup> June 2006 [EILN0000003\_133] all trustee appointments were in the gift of the Secretary of State. I don't know what the exact process for electing trustees was or whether it changed over time. The

re-election of trustees seemed to be a formality although the DOH weren't very efficient in remembering to do it.

**15.**

- a.** I don't remember a situation where Dr Winter's retirement meant that we were unable to access medical expertise that we needed because I don't remember a situation when we needed medical expertise.
- b.** As far as the appointment of another Medical Trustee is concerned, I can't add anything to what is stated in the minutes of 29/10/2008 [EILN0000003\_052] and 10/3/2009 [EILN0000003\_051]. I don't remember why there was apparently some disquiet about the lack of direct clinical expertise.

**16.** I don't know if or how positions were advertised.

**17.** All the trustees I worked with were extremely committed, capable, knowledgeable and effective so, although I don't know how many applicants there were for vacant trustee positions, I have no hesitation in saying that I think the quality of trustees was high. I was not involved in the appointment or re-appointment of trustees.

**18.** According to the Eileen Trust Handbook 1999 [MACF0000176\_002] the ET had five trustees appointed by the Secretary of State and normally three of these nominees would be Macfarlane trustees. During my tenure, the Trust had no 'user' trustees.

**19.** I don't have a record of how long each trustee served on the board. I served from 1993 to 2017. As outlined in the Appointment Protocol [EILN0000009\_099], trustees were appointed for a period of 3 years and tenure was renewable.

**20.** Trustees were not remunerated for their work. I don't know about the policy on allowances or expenses. I don't recall ever claiming any.

**21.**

- a.** There was an overlap of trustees between the MFT and the ET, as expected in the Appointments Protocol (see question 18 above).
- b.** I can't recall why the ET Chairman considered it inappropriate for the next Chairman to also be a trustee of the MFT.
- c.** I had no concerns regarding the overlap of trustees between the AHO because as far as I recall there was never a situation where the overlap impacted on the ET's ability to fulfil its obligations.

Structure of the AHOs

- 22.** I was aware that the AHOs shared premises, staff and resources but I do not remember (and possibly never knew) any more detail than that. I was not involved with how staff were managed because my concern and focus was with/on the registrants and their requests. I do not remember such matters ever being discussed in Board Meetings, which instead focussed on the needs and requests of the Registrants. The rest of the question, therefore, relates to matters outside my knowledge or experience.
- 23.** I have no direct recollection of why the CT acted as employer for all five AHOs. I note that, according to the Annual Report 2012: 'The establishment of Caxton increased the resources (staff and office space) needed for this group of entities to a scale that could no longer be supplied within the confines of MFT's Trust Deed. Caxton therefore assumed the resourcing function, becoming the employer of all staff and taking over the leases of the space in Alliance House occupied by the group.'
- 24.** I had virtually no involvement with the MFT and none at all with the other AHOs so I don't think I can comment on the relationship between them, except to say that the MFT (and later Caxton), employed the staff that ran the ET and several ET trustees were also MFT Trustees. There was never any issue caused by this situation insofar as I am aware. Occasionally there were references at ET board meetings to the fact that the ET was able to operate in a more flexible

way to the MFT but it was not a major topic of discussion. There was also a recognition of the fact that, because there were so few ET registrants, the trustees were able to be more flexible with grant giving than was the case with the MFT. I note that there is a record of my attending an MFT meeting, but I do not remember this.

- 25.** The working relationship between the trustees of the ET and senior management was good and I can't remember there ever being any difficulties.

### Relationship with Government

- 26.** Funding for the ET came from the DOH and the Secretary of State was responsible for appointing trustees, identifying beneficiaries, and determining "eligibility". The ETs remit was to make decisions on the applications and I don't remember the DOH having any involvement as to policies' content, how we discharged responsibilities, the kinds of applications we should grant or the quantum of the grants, either in terms of direction or guidance. That said, as is described in the Annual Reports, at various times the DOH was involved in changes to the structure and organisation of the trust and ultimately it was the DOH's decision to close the ET.

- 27.** There are a number of mentions in different minutes of the uncertainty that was sometimes felt about the DOH's intentions regarding the funding of the ET. After the second tranche of £500,000 was received in March 2002 the Trustees felt that in view of this evidence of continued support for the Trust from the Government, reinforced at regular meetings with Ministers and their officials, the ET could be confident of future funding.

The Chairman had regular meetings with the DOH at which the structure or organisation would have been discussed if it was relevant, eg in 2008/09. I was present at one meeting with the DOH on 6<sup>th</sup> November 2009, although I have no memory of what was discussed. The details of all the meetings with the DOH will have been recorded in the Trust's minutes. Prior to the changes discussed in 2008/09, I can't recall any occasions when the DOH was involved in how the ET was run.

28. I am not aware of any contact between the ET and DWP or its predecessors in relation to welfare benefits.
29. The Chairman and the Chief Executive had regular contact with the DOH, sometimes with a civil servant, and sometimes with the relevant minister. Apart from on 6/11/09, I was not party to these meetings and am not aware of any difficulties.
30. I don't remember what the concerns were about antagonising or embarrassing the DOH, or why they were held. The minutes cited in the question [AHOH0000017] are dated from 1994. I feel confident in saying that as the Trust became more established, and certainly after Peter Stevens became Chairman, the risk of antagonising or embarrassing the DOH over something that the Trust deemed important would not have been considered relevant. I believe that the Trust was always able to advocate adequately for beneficiaries.

The question also refers to identifying new beneficiaries. It was the responsibility of the DOH not the ET to identify people who were eligible however the trust took steps to raise awareness of the ET, both amongst the medical profession, so that potential beneficiaries could apply to the DOH for eligibility, and amongst people who had already been deemed eligible by the DOH and therefore would have been told about the ET by the department. To be clear, the ET wasn't involved in identifying beneficiaries *per se* and potential beneficiaries did not apply to the ET.

#### **Section 4: Funding/finances of the AHOs**

31. Initially, a £500,000 block fund was settled on the ET in 1993. Thereafter the ET would submit requests to the DOH, outlining the case as to where more funding was necessary and the DOH would respond (see chart in answer to question 34). Various special payments and block grants were made but sometimes, as in 2005 when the MFT and the ET jointly put the business case for increased funding to the DOH, it wasn't successful. The answers to questions 32, 34 and 37 may also be relevant to this question.



**32.** I do not know how Government set the budget. The ET was set up with a fund of £500,000 and given a further £500,000 in March 2002. The ET assessed applications and spent the 2 available funds, appropriately and in line with the rules of the Trust, and then in 2003, and on a number of subsequent dates, knowing that more funding would be needed in the future, asked the government for future money, based on the ET's assessment of anticipated needs. The ET did not have a budget in the sense of a level of expected expenditure within a given timeframe.

In December 2005, to enable the Trust to meet its continuing commitments, a business case was submitted to the DOH, jointly with the MFT, for additional funding to enable the Trust to raise its annual disbursements to its community of care to about £250,000. The core of the argument was that the greater length of time that registrants survived their infection, while very welcome, meant greater financial and other needs than when the Trust was established.

These arguments seem to be irrefutable however the business case was not accepted by the Department of Health, and as the chart in Q. 34 shows, the subsequent funding levels were well short of £250,000. I don't know what, if any, reasons the DOH provided for refusing funding but as a result of their decision the ET had to decide to be prepared to make inroads in reserves in order to meet the needs of the registrants. It was also decided to be more selective in awarding single grants, although the increase in rates of regular payments was at the time leading to a generally reduced level of these requests. This is set out in the Eileen Trust minutes from October 2007 [EILN0000003\_054]

From 2007 the Department changed their method of funding the ET to annual awards paid quarterly in arrears – and in 2009 they discontinued the Section 64 grant, hitherto awarded to cover the ET's administration costs.

As the minutes of March 2007 record **[EILN0000003\_127]**, the DOH's funding allocation was deemed unacceptable by the trustees, so clearly in the view of the ET, the DOH did not take sufficient account of the Trust's representations.

**33.** The ET staff and particularly the case worker, provided Trustees with very detailed information about the registrants and their needs. From 2002 a case by case review was conducted at every board meeting to assess needs. I don't know whether this information was given to the Government.

**34.** The figures in the chart below are taken from the Annual Accounts of The Eileen Trust.

<b>FUNDING RECEIVED FROM THE DOH</b>		
<b>YEAR</b>	<b>PURPOSE</b>	<b>AMOUNT</b>
1993	DOH Block Grant	£500,000
2000	Special payments for 2 new registrants	£132,500
2002	DOH Block Grant (received in March)	£500,000
2003	Special payment	£43,500
2005	Special payments for 2 new registrants	£132,500
2006	Restricted Fund	£43,500
2007	DOH Block Grant	£177,000
2008	DOH Block Grant	£140,000
2009	DOH Block Grant	£178,000
2010	DOH Block Grant	£181,705

Following the Archer Inquiry, registrants received a non-discretionary amount per year, starting at £12,800 in 2011 and linked to the CPI. The ET received a sum of money from the DOH for discretionary grants but registrants' need for these was reduced. The Annual Accounts for subsequent years show how much the DOH provided for this purpose.

**35.** My recollection is that the funding was inadequate and that this view was widely held among the ET trustees. That is supported by the minutes of 20/6/07 **[EILN0000003\_055]** and 17/10/07 **[EILN0000003\_054]** which record the view that the level of funding provided by the Government was not adequate. In addition this quote from the Annual Report of 2009 makes clear the Trustees'

views: 'The Trustees believe that the requirement for a reserves policy is met by the DOH's undertaking to continue to fund the Trust on an annual basis, even if the level of this funding is regarded by the Trustees as insufficient to enable them properly to execute the responsibilities which the Government laid on them.'

Again, in 2012 the Annual Report states: 'The Trustees have expressed their acute concern that their response to the needs of their registrants is being governed by Departmental Funding rather than proper consideration of those needs.'

The situation described in Peter Stevens email of 27/11/06 was unusual in that we didn't normally have to deal with back payments. I cannot remember the details of what Peter is referring to, nor do I know why this one was made.

**36.**

- a. Reading the minutes of 28/2/97 [EILN0000006\_159], my understanding is that the Trust had written to the Government saying that there were too many uncertainties in assessing possible future demands on the Trust to be certain that it would be self-sufficient, and that is why the Government had committed to re-examining the financial needs of the ET.
- b. In March 2002 the Government gave a further £500,000 to the ET thereby, at that time, fulfilling their commitment to re-examine the financial need of the Trust.

**37.**

- a. In the first 10 years or so of the Trust, the funding was provided in tranches, as and when it was needed, so the issue of applying for top up or additional monies in a particular financial year didn't arise (see the answer to question 31 above).
- b. I don't know why the discussion about future funding of the Trust in the meeting dated 13/2/08 was not minuted.

- 38.** There was regular contact between the ET Chairman and Chief Executive and the DOH. I did not attend any of those meetings apart from the one with the MFT and the DOH on 6<sup>th</sup> November 2009. The issues that the ET wished to discuss at these meetings were considered by the trustees before the meetings and the results were reported in the relevant minutes. I cannot recall what I was told about the meetings' content, beyond what is in the minutes. I do not know who set the agenda or whether there were any formal minutes of those meetings. I do not recall ever seeing any. The position to be put forward was discussed by Trustees in advance of the meetings.
- 39.** The answer to this question is contained in the answer to question 38
- 40.** The ET had no other streams or sources of funding/income other than that provided by Government during my tenure.
- 41.** I don't remember any particular reason why the Trustees should have thought the Government might have ceased funding the ET. It didn't happen.

Financial management/governance

- 42.** Forecasts of expenditure were presented to the board annually. I don't remember how the grant expenditure was forecast, but the regular payments' and the winter payments' component of the budget would have been forecast based on the number of registrants/beneficiaries we had.
- 43.** The number of registrants/beneficiaries did not greatly change and although over time the money spent on grants increased, this didn't create spikes but more of a gradual increase which was easier to plan for.
- 44.** I don't remember enough about this to be able to comment.
- 45.** The Trustees decided on the level of reserves that the ET should maintain. As is reported in the Annual Report for the year ending 31<sup>st</sup> March 2004 [EILN0000016\_050] the Trustees decided that in view of the evidence of continuing support for the Trust from the Government, reinforced at regular

meetings with Ministers, they believed that the Trust did not need a reserves policy.

- 46.** The Annual Report 2010 states ‘The Trustees believe that, in the light of the Archer settlement and their concerns about the future, it would be prudent to continue to maintain reserves at around the current levels.’ This they continued to do.
- 47.** The timing of our requests for additional funds was affected by the level of reserves that the Trust had, however I am not aware of any other impact on negotiations.
- 48.** The administration and operational work for the ET was carried out by MFT staff in return for a fee paid by the ET. Prior to 2009 the ET received a Section 64 grant which covered these costs, so the amount of money available for beneficiaries was not affected. When the DOH stopped paying the Section 64 grant (last paid in the year ending March 31<sup>st</sup> 2008), Trustees had to cover the costs of administration out of the main grant which was not increased to cover the extra costs. In 2011, in order to reduce costs, the ET’s Case Worker and IFA, Susan Daniels, took over responsibility for administration and was made Secretary of the ET. In subsequent years the admin/governance costs fell considerably.

The figures in the chart below are taken from the Annual Accounts of the ET.

<b>Admin costs/Governance costs</b>		
1995	£16,210	
1996	£15,667	
1997	£18,045	
1998	£26,213	
1999	£25,658	
2000	£24,024	
2001	£25,776	

2002	£28,050	
2003	£31,007	
2004	£32,148	
2005	£35,149	
2006	£36,686	
2007	£37,800	
2008	£41,461	
2009	£32,259	
2010	£38,798	
2011	£34,266	
2012	£20,542	(SD responsible)
2013	£7,662	
2014	£9,515	
2015	£4,582	
2016	£5,585	
2017	£10,534	
2018	£14,330	

The MFT, and later Caxton, was responsible for the salaries of its staff, who also carried out the administrative and operational work for the ET, and I was not involved in arrangements regarding their pay. The only exception to this was Susan Daniels who was paid out of the ET's DOH grant. The minutes of 3/08/11 [EILN0000003\_002] refer to a report by Mrs Eve Rook which recommended that Susan Daniels' salary should be pro rata £27,200.00 or actual £13,603.50 on Scale Point 29 0 SO1 Grade. The board accepted this recommendation having previously decided that her salary should be as near up to £14,000 as possible under the Hay process.

### **Section 5: Identifying beneficiaries for the AHOs**

- 49.** It was the Department of Health's responsibility to identify potential beneficiaries for the ET.
- 50.** The DOH sent a letter to all those who had been identified as having contracted HIV from NHS-supplied blood transfusions and blood products. I don't know if there were any other ways in which potential beneficiaries were identified.

- 51.** In order to raise awareness of its work, the Trust wrote a publicity leaflet and covering letter for a second trawl by the DOH of people who had received compensation. The minutes of November 1993 [EILN0000006\_196] state that the drafts were sent to the DOH. The minutes of February 1994 [AHOH00000017] make reference to a decision to try and reach potential registrants who might not yet have made a claim, or those who had received a settlement payment but were not aware of the ET. According to the Annual Reports of 2002 and 2003 'the DOH will be.....once again bringing the existence and purpose of the Trust to the attention of medical practitioners throughout the country.' It is possible that this was done in other years as well.
- 52.** According to the minutes of October 2002 [EILN0000013\_369], the DOH put an announcement about the ET in the Chief Medical Officer's update because it was felt possible that the ET no longer came to mind when patients were diagnosed as HIV positive and the likely cause could be contaminated blood or tissue. I don't know whether the announcement was successful in raising awareness amongst potentially qualifying people of the existence of the ET.
- 53.**
- a. The efforts to trace children orphaned by the death of registrants was prompted by a wish to see whether they had needs that might have been met by the ET. I do not recall what brought it about.
  - b. I don't know how many orphaned children were subsequently traced and supported.
- 54.**
- a. The ET wrote to the DOH because it was concerned about the slow registration of new members following the 'Liverpool incident'.
  - b. The Liverpool incident occurred in the Autumn of 1996 and was when a number of people, other than those with haemophilia, were infected with HIV as a result of treatment of contaminated NHS blood products.
  - c. According to the minutes of January 1998 [EILN0000006\_128], the DOH's response was to outline staffing difficulties. This doesn't feel like an adequate response.

**55.** I don't know if there were more eligible people in Liverpool who were never registered. If there were, it is regrettable that the DOH were not sufficiently resourced to identify them.

### **Section 6: Eligibility for the ET**

**56.** The DOH set the eligibility requirements for applications to the ET. I don't know what evidence an applicant had to produce to prove eligibility.

**57.**

- a.** I don't know if the eligibility requirements were publically available or where they could be accessed.
- b.** See my answer to 57(a).
- c.** The DOH informed medical practitioners about the ET but I don't know if that involved outlining the criteria for eligibility.

**58.** I was not consulted about the eligibility requirements, or otherwise involved in formulating them.

**59.** I am only aware of the overall requirement which was to have been infected with HIV as a result of treatment of contaminated NHS blood products. I am not aware of the detailed requirements e.g. burden of proof. I don't remember receiving any information concerning changes to requirements.

**60.** I have no recollection of the 'ground of technicality' that prevented the new registrant being eligible for financial assistance

**61.** This question relates to matters outside my knowledge or experience. I am not aware of the eligibility requirements for other AHOs.

**62.** This question relates to matters outside my knowledge or experience.



- 63.** As noted in my answer to question 56, the DOH set the eligibility requirements for the ET. I don't know what evidence an applicant had to produce to prove eligibility.
- 64.** Given that the ET was not involved in setting, writing or reviewing the eligibility requirements, approving applicants for eligibility, or dealing with any concerns or dissatisfaction, I am not able to answer this question. As I have explained above, the DOH was responsible for locating beneficiaries and determining their overall eligibility. The role of the ET was to determine what financial assistance a beneficiary might require, by approving applications for grants.
- 65.** See question 64.
- 66.** See question 64.
- 67.** See question 64.
- 68.** See question 64.
- 69.** See question 64.

## **Section 7: Decisions on substantive applications within the ET**

### *The process*

- 70.**
- a.** Some ET Staff, but I don't know which ones, were allowed to approve, but not refuse, a certain level of applications for grants within limits set by the Trust. In the ET Handbook [MACF0000176\_002] it states: 'For many of the more common types of payment the Trustees have authorised the staff to make immediate payments, providing that the application falls within limits set by the Trustees.'
  - b.** All decisions on applications (apart from the ones mentioned in 70(a)) were made at board level. No committees were ever formed.
  - c.** See my answer to 70(b).

**71.** There were no formal policies (either written or unwritten) to determine applications. The number of registrants was so small and their needs were so varied that it would have been difficult and not particularly useful to have policies, whether written or unwritten, apart from the overall policy of fulfilling the purpose of the Trust, as outlined in the Trust deed. Trustees had very detailed knowledge of the financial situation regarding all the beneficiaries and that meant we could be confident of the decisions that we took regarding individuals' need and the appropriateness of any discretionary grant we might give them. However in 2010, after Archer, the Trust agreed guidelines as to the minimum level of annual income that registrants should have, depending on their circumstances, which were £18,000 for a single person living alone and £30,000 for somebody living with a partner.

**72.**

- a.** The procedural requirements for an application were set out in the Eileen Handbook. Applicants could either fill out a form which contained all the required information, or write a letter. I do not know who originally produced the form. Once Susan Daniels was the Case Worker, the ET's communication with the registrants was much closer and the majority of applications came through her.
- b.** I do not recall whether they were reviewed.
- c.** I was not personally aware of beneficiaries being unable to satisfy procedural requirements.

**73.** The vast majority of applications were granted wholly or in part. If they were refused it would probably have been because we didn't think they fell within our remit. If they were only granted in part it would have been because we thought that was the appropriate action to take.

**74.** I don't know the answer to this question

**75.** ET staff were able to deal with grant applications that fell within limits fixed by the Trustees. According to the ET Handbook, in most cases this covered 60% of the applications and requests were usually cleared within a week. Urgent

requests for grants that fell outside the ET staff remit were considered by the trustees via email or telephone communications outside normal board meetings.

**76.** The Case Worker, Social Worker, Benefits Adviser or other ET staff were available to help them.

**77.**

- a.** ET registrants were made aware of what financial assistance was available to them via the handbook and ET staff.
- b.** ET registrants were supported in non-financial matters by ET staff who were available to visit or talk on the phone, and by a helpline.
- c.** I was not involved in personally supporting beneficiaries.

**78.**

- a.** The ET combatted the concern that registrants might have been reluctant to ask for help in a number of ways, including:
  - In the early days of the Trust the case worker or social worker would have contacted registrants on an occasional basis to offer a visit or an opportunity for a personal discussion on the phone,
  - Reviewing on a regular basis, each person or family's circumstances and the help that the Trust gives them. After 2002 this took place at every trustees meeting.

We believed that these precautions were sufficient. Over time, as registrants had more and more contact with the Trust, I don't think there was a reluctance to ask for help.

- b.** I don't know enough about how the MFT worked to be able to answer this question.

**79.**

- a.** I don't remember the outcome of the research or whether any changes were made to the ET as a result.

- b. It was felt that ET registrants might be interested in attending some of the MFT seminars given the subjects they covered, and there are several references in the ET minutes to registrants attending them and finding them useful, for example the minutes of October 1998 [EILN0000006\_079] refer to trustees agreeing to fund 2 registrants who wished to attend a MFT seminar weekend for 'positive women.

80. I have taken the figures below from the Annual Reports but I'm not 100% sure that they include everyone supported by the ET in the early years. There is not total consistency in the way that the numbers are presented, so different years are not always comparing like with like. The figures from 2004 onwards are, I believe, accurate.

YEAR	Registrants	Infected intimates	Widow/ partners	Dependant children under 18	Young people under 25	Registrants and other qualifying beneficiaries (these figures are totals)
1996	12	2				
1998	9	1	7	13		
1999	9	2				
2000	10	2		14		
2001	10	2		13	3	
2002	10	2		12	5	
2003	11	2		12	6	
2004				12	6	28
2005				5	11	28
2006				1	5	28
2007				1		27
2008						23
2009	16					23
2010	16		3	1		21
2011	16		3			
2012	16		3			
2013	15		1			
2014	17					
2015	17					
2016	17					
2017	19					
2018	19					

From 2015-2018 the ET supported a small number of dependents of deceased registrants.

- 81.**
- a.** Regular payments were made to beneficiaries at rates varying according to circumstances eg whether they were on Income Support. A supplement was sometimes added for health reasons.
  - b.** Details of the lump sum payments made to registrants can be found in the government policy paper [PRSE0004024] which states: 'HIV infected individuals received lump a sum of £20,000 each in 1990, and an additional lump sum in 1992 of up to a maximum of £80,500 (for a married individual with children).' I don't know for certain if these amounts were increased later but I don't think they were.
  - c.** Details of the payments or grants that were made are in the Annual Reports of each year. Each application for support was assessed individually, based on the circumstances of the registrant and approved if they were deemed to come within the terms of the Trust Deed.
- 82.** I don't think it was Trust policy but I can't remember enough to answer the question adequately.
- 83.** The success or otherwise of an application did not depend on the number of applications made per year, each application was considered on its merits
- 84.** The vast majority of applications were granted wholly or in part.
- 85.** Each application was considered on its merits which included assessing any benefits that individuals received from us or from other sources. All the applicants received some level of regular payment from the ET but this did not mean they weren't in financial need. Decisions whether or not to award grants were taken after detailed individual reports from the case worker.
- 86.** The grants were discretionary and were based upon financial need as judged by the Trust. The Trust took the view that anyone with HIV had financial needs in connection with trying to preserve their health, and the majority of our

registrants were on Income Support. Peter Stevens' email of 13/11/06 outlines the position of the Trust. There were no "income brackets" applied – we were able to make an assessment of need in each individual case, relying on the case-workers reports.

**87.** In my view, the Trustees put a lot of time and thought into maintaining consistency and fairness in the decision making. ET registrants' needs were very different from each other and the requests covered a variety of needs that could often not be compared with each other.

**88.** It was my role as a trustee to ensure that money was distributed appropriately. This sometimes included having to query whether the purpose for which the money was sought, and the amount sought, was appropriate. In this email exchange I raise a valid query as to whether the trip was suitable to be funded in full. There would have been further discussion between trustees following the email exchange but I don't recall what the final outcome was.

**89.**

- a. I don't remember enough detail of the meeting to be able to answer this question.
- b. I don't remember enough detail of the meeting to be able to answer this question.
- c. I don't remember enough detail of the meeting to be able to answer this question.
- d. My understanding from the Annual Report 2006 is that: 'Regular payments are also made in some situations to needy relatives of registered people who have died. There is no set pattern to these and discretion is applied according to the individual circumstances'. This would suggest that by 2006 support for widows was the same as for dependents but I don't think I can say whether it was satisfactory or not. I cannot remember now my view of this at the time, but I assume I thought the support should be the same.

## **Section 8: Complaints and appeals**

90. The ET Handbook [MACF0000176\_002] gave details of how a registrant could ask for a review of a decision on an application or could register a complaint. I have no personal knowledge of the appeals or complaints procedure.
91. I have no recollection of any appeals being launched during my tenure.
92. The ET Handbook [MACF0000176\_002] gave details of how a registrant could ask for a review of a decision on an application or could register a complaint.
93. I have no recollection of any complaints being made.
94. The ET Handbook [MACF0000176\_002] gave details of how a registrant could ask for a review of a decision on an application or could register a complaint.

## **Section 9: Engagement with the beneficiary community**

95. The ET beneficiaries were not a community in the same way that MFT beneficiaries were, since they had become infected through a great variety of circumstances, therefore communication with them was best done on an individual basis with the relevant member of staff. The ET staff were in regular contact with the beneficiaries and through their work the Trust was able to understand the beneficiaries' needs.
96. Even though the Secretary's Report [EILN0000003\_183] talks about my input, I have no recollection of the newsletter. I expect that my involvement would have been in presentation and style rather than content.
97. In the early years of the Trust there was discussion about having an annual event for beneficiaries but for various reasons this only happened later on. In the latter years of the Trust's life there were annual weekend gatherings of registrants. The main purpose was to support the beneficiaries, all of whom were invited. These events were attended and appreciated by most of the registrants and helped build relationships with each other and with the Trust. I

don't know who set the agenda. There were no problems encountered in running the meetings and I believe they encouraged closer understanding on all sides.

**98.** The relationship between the Trustees/senior management and the beneficiary community was good. There was a lot of contact between ET Staff and registrants and in many cases the registrants were helped with issues like managing debt, especially after the appointment of Susan Daniels who had more direct contact with registrants than her predecessors. From 2008 the Trustees and the registrants met at the Annual events which I think further helped the relationships involved.

#### **Section 10: Relationships with other organisations**

**99.** This question relates to matters outside my knowledge or experience. I had no involvement with the Haemophilia society.

**100.** See my answer to question 99.

**101.** See my answer to question 99.

**102.** See my answer to question 99.

**103.** See my answer to question 99.

**104.** I wasn't in touch with any clinicians during my work with the ET, apart from seeing Dr Mark Winter at Trustee meetings.

#### **Section 11: Reform of the ET**

**105.** At different times during my tenure as a trustee changes to the organisation was a subject that was discussed at the board. The 2016/2017 reforms are addressed in my answer to question 108.



**106.**

- a. I understand that the discussion about merging the ET with the MFT were prompted by the Government's reaction to the Archer Inquiry recommendations.
- b. Had the merger happened, I don't think that there would have been any advantages to ET registrants. Possible disadvantages are outlined in my answer to question 108.

**107.** The changes felt like a step, but only a step, in the right direction since they gave registrants more money and more control over their lives.

**108.** I was concerned that our registrants, who for so many years had been part of a small organisation where they had established relationships, would feel lost in the new arrangement. I didn't know if they were going to still have access to Susan Daniels, but if that was not going to be the case, I thought it would have been extremely regrettable, since she was such a useful and supportive part of their lives. Equally importantly, Trustees were also concerned that, under the new arrangements, registrants wouldn't have access to discretionary grants which in all probability would still be needed.

The ET's concerns about the 2016/17 reforms were made clear in the Annual Report 2016: ' The Trust and many of its beneficiaries have responded to the Department objecting to this proposed cessation of the Trust , whose beneficiaries have expressed their distress at the possible loss of the services, support and fellowship they receive through the Trust. Other proposals would have removed the index-linking of the payments made by MFET and restricted possible financial grant support, of the type currently given by the Trust, to travel and accommodation costs relating to ill-health. These financial proposals would, in the view of the Trustees, have had a deleterious effect on the finances of all the Trust's beneficiaries, in a few cases substantially so. The Trustees pointed out these unacceptable effects to the Department'.

**109.** In June 2016 the DOH responded to the issues raised by the Alliance House organisations in January 2016. The proposals in their response that affected the ET registrants can be read on page 5 of the Annual Report 2016.

110. I don't remember if either I or the ET raised any objections to the changes but, according to the Annual Report 2017 [EILN0000016\_029] there was a consultation on the proposals in March 2017, which suggests concerns had been raised. Regrettably, the Annual Report 2018 makes no mention of the 'consultation' and the ET's functions were subsequently transferred to BSA. I was no longer a Trustee at this time but I totally concur with the statement on page 4 of the Annual Report, which reads as follows:

**“The Trustees objected to the Department’s replacement of the Trust, as have many of its beneficiaries, conveying their distress at the loss of the services, support and fellowship that they have been receiving through the Trust. The Trustees were also disappointed not to have seen the business case for the transfer of Trust’s activities to BSA”**

111. I was no longer a Trustee when the transfer took place and this question is outside my knowledge.

### **Section 12: Other**

112. My fellow trustees were knowledgeable, conscientious, open minded and constantly trying to do the best for the ET registrants. The Executive Office was efficient, effective and sympathetic. The Trust made good use of the money allocated to us and I believe that that Martin Harvey, Peter Stevens and their predecessors worked very hard with the DOH to ensure that the ET received sufficient funding for the Trust to fulfil its aims. Although the DOH ultimately seemed to pay little attention to the concerns of the ET regarding the 2016/17 changes and organisation, the ET chairman, Peter Stevens, never stopped working to try and protect the rights of the registrants and their access to the support that he had done so much to ensure was available to them.

113. In my view, the biggest change to the ET was that over time, we became much closer to the Trust's beneficiaries and as a result were much more useful to them. Unlike the MFT beneficiaries the ET beneficiaries didn't have any organisations related to their situation, so I believe that the relationship they

had with the ET and the ET staff was particularly supportive and helpful. The appointment of Susan Daniels as case worker was absolutely key to this relationship and to the Trust's ability to carry out its responsibilities. As was stated in the 2006 Annual Report:

'The appointment of Susan Daniels as the Trust's Case Worker has led to a significant improvement in the Trust's understanding of its community of care. This enhanced relationship has resulted in the increase of financial support to the beneficiary cohort'

Of course the money the ET gave the registrants was crucial, but the personal contact, the belief that someone was fighting their corner was equally important. I believe that the whole of the ET but especially Susan, helped to engender that feeling.

**114.** I have nothing more to add.

**Statement of Truth**

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

Signed

GRO-C

Dated: 26<sup>th</sup> January 2021