

28 January 2014

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House of Commons
London
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Dear Diana and Jason

APPG Inquiry Report

Thank you for allowing us to see an advance copy of the APPG Inquiry report, prior to its publication on 14 January 2015. We would also like to take the opportunity to thank Jason for meeting with us to discuss the report on 13 January.

Although we have not been invited to submit a formal response to the report, I am writing to give comments on it on behalf of the five Alliance House organisations discussed in it: the Macfarlane Trust (MFT), the Eileen Trust, the Caxton Foundation, the Skipton Fund, and MFET.

Overall we welcome the report and the opportunity it has given beneficiaries to express their views about a range of issues. In the context of the limited resources available to us, we have been pleased to assist with the APPG's Inquiry, including distributing the letter about the survey to approximately 2000 people registered with us, and providing as much information as possible, both at the meeting in September 2014 and subsequently by letter and email.

Whilst there is a tendency in the report to focus on and quote negative, rather than positive, comments made about the organisations, we feel that the report overall is balanced and acknowledges the constraints – particularly the financial constraints – which give rise to much of the criticism about the way we operate. The Alliance House organisations are well aware of the dissatisfaction of some beneficiaries with the fact that successive Governments' response over the years has been to set up 5 organisations – 2 companies and 3 charities – to provide non-discretionary and discretionary support as opposed to providing any final settlement. Beneficiaries' dissatisfaction is compounded by the fact that the charities are not funded at a level which could meet many beneficiaries' expectations, and also have to be able to determine charitable need when making any form of discretionary payment. Therefore many of the criticisms in the report are not unfamiliar to us. However, we were pleased to see that in the survey, the majority (65%) reported a positive or neutral experience of engaging with us. We are committed to continuously improving our performance and responsiveness, and the range of services and advice that we offer, subject to funding.

We were interested to see that the report revealed a perception amongst many that the organisations have what amounts to a "cosy" relationship with the Department of Health (DH). Whilst we would describe our relationship as cordial and professional, it is certainly not cosy. As the APPG is well aware, we are given an annual allocation and advised to "manage within our means". Even when we have

identified need within the beneficiary community and submitted business cases, these have not been approved and DH has repeatedly told us that funding is tight. We have therefore been left to feel that we are fortunate that our funding has not been cut. However, there is no guarantee that funding will not be cut in future years, and we are concerned that this may already be under consideration for 2015/16. Given its existing deficit position, MFT has already expressed its concerns to DH regarding the 2015/16 allocation.

The report contains many factual inaccuracies, which cause confusion and give an inaccurate picture of the way the organisations operate in practice. Whilst we do not believe the errors significantly undermine the recommendations, we feel we must provide a correction to these. These are therefore attached at Appendix 1.

The APPG has produced an interesting set of recommendations, most of which, as noted below, will be for Government to consider. However, we set out below our responses to each of the recommendations in turn:

1. **Government should review the system of support again, including:**
 - **Considering mergers** – this will be for Government to consider. However, Caxton and MFT would not oppose this in principle. They recognise the efficiencies that could be achieved by the small staff team not needing to service the governance requirements of multiple organisations (boards, audits etc) and the opportunity it would give to address some of the anomalies in the differences in support which the two larger charities provide. However, both charities would stress that mergers would only be able to achieve positive outcomes if any new, merged charity had additional resources, including DH lifting its cap on staffing levels. To merge them without this, when both currently have additional funding requirements, would result in no positive improvements for beneficiaries and would be likely to provoke additional and continuing criticisms. The Eileen Trust is less supportive of the idea of mergers, as it is concerned that its small number of beneficiaries, who currently benefit from a close relationship with the organisation, would be disadvantaged.
 - **Further publicity of the organisations** – we believe this has been addressed by the Skipton look-back exercise which was carried out from September 2014 onwards. Several hundred people who had received Skipton Stage 1 payments – many before Caxton was established in 2011 – registered with Caxton as a result.
 - **Reviewing Skipton criteria etc** – for Government to consider. Skipton is unable to comment due to the restrictions in its agency agreement with DH.
2.
 - a) **Organisations to advertise the support available** – during 2014 Caxton and MFT have done significant work on this in order to be much more transparent about the support they are able to provide, including substantially updating both websites and sending written updates to all beneficiaries towards the end of 2014; the updates will be sent on a regular basis.
 - b) **Assist people who have difficulty in applying/completing forms etc** – all three charities already do this. Staff frequently assist people with filling in forms and helping to identify supporting paperwork for grant applications. They also sometimes contact suppliers and contractors on behalf of beneficiaries when beneficiaries do not have the confidence to do this themselves.
3. **Specialist service to assist registrants unable to obtain payments due to insufficient medical evidence or hospital records** – for Government to consider. Skipton is unable to comment due to the restrictions in its agency agreement with DH.

4. **People with haemophilia should not be denied Skipton payments because the NHS lost their medical records** – for Government to consider. Skipton is unable to comment due the restrictions in its agency agreement with DH.
5. **Window of opportunity to claim Skipton payments for people infected who died before August 2003 should be permanently reopened and advertised widely** – for Government to consider. Skipton is unable to comment due the restrictions in its interagency agreement with DH.
- 6, 7, 8 **Public Health doctor should be seconded to all 5 entities to carry out a comprehensive needs assessment and decide what level of payments everyone should receive and what level of funding the 3 charities should receive** – for Government to consider. Whilst we would welcome a review of appropriate funding levels for the charities, independent of DH, we are not convinced that it would be appropriate for a single public health doctor to undertake such a review. Since the APPG report was published, some beneficiaries have already contacted us likening this proposal to ATOS undertaking ESA assessments, which the APPG will be aware is deeply unpopular with the beneficiary community. Any conclusions would also need to be mindful of the fact that the charities cannot disburse money equally to all beneficiaries, and consideration needs to be given to the key factors of trustee discretion and the requirement for charities to determine charitable need. In relation to the two companies, Skipton and MFET, as payments are non-discretionary, these are not made based on need in the way that charitable payments are.
9. **Setting up an independent adjudicator for people to go to if they don't like our decisions** – for Government to consider. However, this recommendation would seem disproportionate given that most applications are for relatively small sums of money. The Skipton Fund already has an independent appeals panel in place and with regard to the charities, we do not believe an independent adjudicator could, technically, countermand decisions resulting from the application of trustee discretion. It should also be remembered that the Charity Commission acts as the regulator for charities.
10. **Portion of each charity's trustees to be drawn from beneficiary population and Haemophilia Society being allowed to appoint 3 Caxton trustees** – we do not believe that any changes to board composition should be contemplated before consideration has been given to the potential for mergers. It should be noted, however, that the composition of the individual charity boards is at the discretion of the trustees. The most important factor is having an appropriate skill mix amongst trustees so that the boards can discharge their responsibilities effectively under charity law. In relation to the Haemophilia Society appointing three Caxton trustees, this would seem inappropriate when less than 50% of the Caxton beneficiary community has a bleeding disorder.
11. **Ongoing regular payments of some kind for those at Skipton Stage 1** – for Government to consider. Skipton is unable to comment due the restrictions in its agency agreement with DH.
12. **Providing fixed ongoing support for widows of those with Hepatitis C, in the way those with HIV receive** – Caxton is in the process of introducing some discretionary, regular support for widows through its new regular payments scheme. However, the type of support that can be provided to any subsection of the charities' beneficiary communities will always be subject to the funding available to the charities in any one year and at the discretion of trustees. The charities could never guarantee any continuation of different forms of support from one year to the next.
13.
 - a) **Public apology from the Prime Minister** – for Government to consider.
 - b) **Priority access to NHS treatment and best therapies available** – this is for Government to consider. However, we are fully aware of the significant negative impact that current

interferon-based treatment can have on some beneficiaries, including unpleasant side effects that persist even after treatment has ceased, and the fact that treatment for some is not successful even after multiple attempts. We would therefore support moves to make newer treatments available to all.

We look forward to seeing the Government's response to your report and recommendations in due course.

Yours sincerely

GRO-C

Jan Barlow
Chief Executive

cc Jane Ellison MP, Under-Secretary of State for Public Health
Alistair Burt MP
Ailsa Wight, Department of Health
Rowena Jecock, Department of Health

Appendix 1

Factual inaccuracies in APPG report

- p3 Paragraph 5 – the Skipton Fund, as well as the other 4 Alliance House organisations, also participated.
- p7 Under “Caxton Foundation” – it should be noted that those without a bleeding disorder who are co-infected receive support from the Eileen Trust.
- p8 Under “Secondary infectee” – we are not aware of any secondary infectees who were infected by treating their child for a cut. Secondary infectees have been infected either through sexual contact or from a mother passing the infection on to their child in utero.
- p10 Paragraph 2 – we never give out vouchers for food. If someone needs support for basic living costs, typically whilst they are waiting for benefits to come through, we will give direct financial support. This factual error is repeated throughout the report.
- p10 Paragraph 3 – we consider that the issue of under-registration with Caxton has been addressed by the Skipton look-back exercise which was carried out from September 2014 onwards and has resulted in several hundred new Caxton beneficiaries coming forward.
- p10 Paragraph 4 – it is implied that people have to prove how they were infected to Caxton as well as Skipton. This is incorrect. The only criterion for being eligible for support from Caxton is that a primary beneficiary must have received a Skipton Stage 1 payment.
- p10 Paragraph 4 – there is no ambiguity in proving viral infection with hepatitis C as it involves a simple blood test. If an applicant is hepatitis C PCR negative without having undergone treatment to eliminate the virus then they are currently excluded from the scheme; these applicants are deemed to be “natural clearers” of hepatitis C. If the applicant is able to prove infection lasted beyond the acute phase, the first six months, then a payment can be made. This is, however, considered to be extremely rare and there is a degree of ambiguity in proving this unless historic PCR test results are available. The majority of applications considered by the Appeals Panel are with respect to claims where there is no evidence of the source of infection rather than whether or not the applicant has/had chronic hepatitis C.
- p13 Section 10 – it is not true that only those at Skipton Stage 1 can get grants from Caxton. People in receipt of Skipton Stage 2 do apply for, and receive, grants, winter fuel payments and other support from Caxton.
- p14 Paragraph 1 – in almost all cases HCV testing is straightforward. The majority of applicants are able to prove their eligibility for the Skipton Fund. The rejection rate of 16% includes all types of rejected applications, including, but not exclusively: “natural clearers”, IV drug use as a risk factor; those treated with non-NHS blood; those not diagnosed with hepatitis C; those treated after September 1991; those treated by blood products considered safe; as well as those where there is a lack of evidence of treatment with NHS blood products.
- p15 Paragraph 1 – almost no applications are rejected on the grounds of insufficient proof of ‘Stage 1 HCV infection’.
- p15 Paragraph 1 – it is not true that the most accurate way of proving HCV infection is a biopsy, it is in fact a simple blood test.
- p15 Paragraph 1 – unsuccessful Stage 2 applications from living applicants are deemed to be ‘deferred’ rather than ‘rejected’ due to the progressive nature of the hepatitis C virus.
- p15 Paragraph 1 – possible explanations for the slightly higher number of successful Stage 2 applications for people without bleeding disorders were provided to the Haemophilia Society on request. At that time it was made clear that biopsy data is often not provided for Stage 2 applications with respect to people with *and without* bleeding disorders.

- p15 Section 14 – it may have been true in the past that beneficiaries were not kept up to date regarding the progress of their application or given a reason for any decision to decline support, but this is not the case now.
- p16 Section 14 – we believe decisions are consistent. It should also be noted that decisions are made by the board/subcommittees of the board, not by staff.
- p17 Section 16 – It is incorrect to say that if the partner of someone infected remarries following their partner's death they lose entitlement to any trust-based support. The only support that widows/widowers who have remarried cannot access as a result of their new marital status is regular payments from Caxton. This misunderstanding is also repeated on page 91, paragraph 3.
- p18 Paragraph 2 – it is not true that people who cleared the virus prior to Skipton's establishment are not entitled to any payments. The same rules regarding clearance apply to those who cleared the virus before and after the establishment of the Fund.
- p19 Section 4 – the Skipton Fund has access to the UKHCDO database of people treated with clotting factor prior to HCV screening so people with haemophilia, in almost all cases, do not need to provide proof of such treatment; consequently, this is very rarely an issue with Skipton Fund applications.
- p19 Section 5 – the window of opportunity was to register the application, not to obtain the lump sum. Applicants who wish to register after the cut-off are urged to contact the Skipton Fund and no application has been declined on the basis of late registration.
- P26 Paragraph 5 – natural viral clearance occurs in approximately 15-30% of cases, it is natural clearance after the acute phase (first 6 months) that is considered to be a very rare occurrence, <1%.
- P27 Paragraph 1 – hepatitis C, not cirrhosis, is treated with ant-viral drugs.
- p32 Section c – it is regrettable that the report implies that we withheld information. The information that we were not able to provide was either not available as it was not routinely collected, or because it had been superseded by later papers, which were provided. This was clearly explained to Thomas Stephens at the time.
- p36 Paragraph 1 – the families of an HCV infected person who died *before* the Skipton Fund was established are also entitled to claim a lump sum payment at any point.
- p41 First row of table – the Caxton regular payments scheme will make payments to eligible widows.
- p41 Second row of table – none of the organisations make any payments for children every summer.
- p42 Fourth row of table - Caxton rarely pays in vouchers.
- p43 Second row of table - MFT also provides respite breaks, associated with respite after treatment and changes to medication.
- p48 Section a, paragraph 2 – whilst MFT has not had any uplift in funding in recent years, we have never been told by DH that our funding has been "frozen".
- p49 Paragraph 3 – it is stated that none of the charities account for any additional costs associated with being infected. This is incorrect. The charities address this issue by always excluding DLA from calculations of household income.
- p54 Bullet point 1 – this funding was, and continues to be, given to, and administered by, MFET.
- p54 Bullet point 2 – funding for MFT and Eileen Trust was **reduced**, not increased, following the introduction of MFET.
- p57 Paragraph 2 – charities provide discretionary, not **non**-discretionary support.
- p60 Paragraph 4 – the figure of 13% here is incorrect, the figure of 11% used in the table on the previous page is correct. Although it is correct that this group of people are registered with the Skipton Fund, in most cases they received the £25,000 Stage 2 payment 8-10 years ago and have

not had contact with the Fund since. It has not been possible to find this group using the contact details they registered with the Fund or through their doctor.

- p61 Paragraph 2 - DH asked **Skipton**, not Caxton, to undertake the look-back exercise.
- p63 Paragraph 1 – HCV infection is detected by means of a simple blood test, not by biopsy. Biopsy data is not required for either stage of application but certainly not for Stage 1.
- p63 Paragraph 1 – people with haemophilia who undergo a liver biopsy solely for the purpose of proving HCV infection are not excluded from the scheme. Proving HCV infection could and should have been done with a simple blood test and, rather than being excluded, applicants are merely asked not to undergo a biopsy solely for the purpose of making a claim due to the small risk involved.
- p63 Bullet point entitled “Proving Stage 2 HCV” – applicants’ doctors must show that it is more likely than not that their patient has developed cirrhosis, rather than that they are more likely than not to progress to it.
- p63 Bullet point entitled “Proving Stage 2 HCV” – fibroscan measures liver stiffness rather than the level of fibrosis, although there is a strong positive correlation between the two.
- p63 Paragraph 4 – there is no judge on the Appeals Panel and no appointments were made by the Department of Justice. The Panel is chaired by an experienced lawyer and all appointments were made by the Appointments Commission.
- p63 Paragraph 5 – Stage 1 applications are either approved or rejected, Stage 2 applications with respect to living applicants are either approved or deferred due to the progressive nature of the disease. Stage 2 applications with respect to deceased applicants are either approved or rejected.
- p64 Paragraph 3 – people with haemophilia who were unsuccessful with their Stage 1 application would have been rejected, in almost all cases, on the grounds of “natural clearance” rather than a lack of evidence of treatment with NHS blood or blood products.
- p66 Paragraph 1 – the Fund’s email to the Haemophilia Society of 24 October 2014 provided various reasons why there might be a slightly higher Stage 2 success rate for people without haemophilia. Biopsy data is often not available for applications from people without haemophilia as well as from those with haemophilia.
- p66 Paragraph 2 – the explanation provided on footnote 125 is not clear. The Fund feels it is likely that people without haemophilia, who are not in a known risk group for hepatitis C, are diagnosed with the virus many years later than those with haemophilia; they would therefore have had fewer years during which to attempt viral clearance. This is supported by the fact that 1/3 of new Stage 1 applications, almost all of which are from people without a bleeding disorder, already qualify for the Stage 2 payment by the time of their diagnosis with hepatitis C. Of course, not all people with haemophilia have attempted HCV treatment and of those who have, not all have achieved a sustained virological response; although the same is true for people without haemophilia.
- p66 Footnote 125 – the increased likelihood of the availability of biopsy data to exclude cirrhosis in the non-haemophilia community would have the effect of reducing the deferral rate in this group rather than inflating the success rate.
- p66 Paragraph 3 – as before, it would be extremely rare for a person with haemophilia to be rejected for a Stage 1 payment on the basis of a lack of evidence of treatment with blood products rather than due to “natural HCV clearance” and biopsy data is often not supplied for Stage 2 applications from either group.
- p72 Paragraph 3 - if someone was registered with Caxton at the time the winter fuel payment was made, they would have been contacted about it and asked to confirm their bank details, and complete a registration form if one had never been received.

- p74 Paragraph 1 - 13 days is the average turnaround time from receipt of completed paperwork to NWC decision, not the time after NWC decision to a beneficiary being notified of that decision, which is 2 days.
- p89 Paragraph 2 - MFT's top-up payments are discretionary, not non-discretionary.
- p91 Paragraph 4 – the payments made by the existing entities were never intended by Government to be **compensation**.
- p95 Paragraph 2 - during 2014 Caxton and MFT have done significant work on this in order to be much more transparent about the support they are able to provide, including substantially updating both websites and sending written updates to all beneficiaries towards the end of 2014; the updates will be sent on a regular basis.
- p95 Paragraph 2 - all three charities already do this. Staff frequently assist people with filling in forms and helping to identify supporting paperwork for grant applications. They also sometimes contact suppliers and contractors on behalf of beneficiaries when beneficiaries do not have the confidence to do this themselves.
- P95 Paragraph 4 – in almost all cases people with haemophilia are not required to provide evidence of treatment with NHS blood or blood products. However, people with haemophilia who are HCV PCR negative without having undergone treatment will need to provide evidence that it is more likely than not that they experienced a chronic infection prior to "natural clearance".