

Witness Name: Glenn Wilkinson

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INFECTED BLOOD INQUIRY

EXHIBIT WITN2050105

The Caxton Foundation

Partnership Group

Notes of a meeting of the Caxton Foundation Partnership Group held at 2pm on 5 August 2014 at
IBIS Birmingham Central, Ladywell Walk, Birmingham B5 4ST.

Present: Ann Lloyd - Chair of the Caxton Foundation
Charles Lister - Vice Chair of the Caxton Foundation
Jan Barlow – Chief Executive of the Caxton Foundation (and the Macfarlane Trust)
Victoria Prouse – Director of Operations of the Caxton Foundation
Liz Carroll - Chief Executive, the Haemophilia Society
[GRO-A] – Manor House Group
[GRO-A] – Manor House Group
[GRO-A] – Tainted Blood
Glenn Wilkinson – Contaminated Blood Campaign

Apologies: Charles Gore – Chief Executive, Hepatitis C Trust
[GRO-A] – widows' representative
[GRO-A] – Tainted Blood
Dan Farthing – Chief Executive, Haemophilia Scotland

1. Welcome and introductions

AL welcomed everyone to the meeting and everyone introduced themselves.

CL noted the meeting was once again being recorded and asked whether other members of the group were happy for it to be recorded; no objections were raised.

2. Minutes of the last meeting

The minutes of the meeting held on November 2013 had been circulated with the agenda and were agreed as a correct record, subject to the following:

- i) GW advised that Ralph Shepperson had been in attendance at the meeting as a carer but had not formally taken part.
- ii) It was agreed that action points and timescales be noted in future minutes
- iii) [GRO-A] advised that at the last meeting he had expressed the view that any regular payments system should be designed to bring income up to reflect the national average wage.

3. Matters arising

i) Recruitment of board member with experience of living with Hepatitis C

AL notified the group that following interviews at the end of last year, Margaret Kennedy had been appointed as a new board member of the Caxton Foundation.

The group had previously asked to know more details regarding how Margaret Kennedy had contracted Hepatitis C.

With MK's consent, AL advised the Group of MK's medical history.

GW expressed concern that yet another Caxton Board member had been appointed who had either an NHS or Department of Health background.

AL explained that Caxton had undertaken a thorough recruitment process and had selected the best candidate for the role; the recruitment panel could not discriminate based on candidate's occupations.

[GRO-A] felt that there should be someone with haemophilia and someone with experience of living on benefits on the Caxton board. AL agreed to feed this back to the board.

ii) Staffing

JB informed the group that Victoria Prouse had now joined the organisation as the Director of Operations and that Joyce Materego would be joining later in the month as the Director of Finance.

DF asked how many staff worked for Caxton. JB advised there were three and a half full time equivalent staff. There were nine staff employed across the five Alliance House organisations. It was noted that the Department of Health had put a cap on Alliance House staffing. Some members of the group felt there should be more staff, but AL and JB advised that more staff would mean less money spent on direct beneficiary support.

LC suggested that the campaign groups and the Haemophilia Society, through the APPG, lobby the Department of Health to give Caxton more money for staffing, without reducing the grants budget. This proposal was not welcomed by everyone.

iii) Business case to Department of Health

In response to a question from [GRO-A], JB advised that the allocation from the Department of Health for 2014/15 was £2.38 million. It was agreed to circulate a copy of business case to the members of the group. AL advised the group of reasons why the business case had been declined by the Department of Health.

iv) Winter fuel payments

JB advised that the board of Caxton had agreed to make a another non-means tested payment of £500 to primary beneficiary households and widows for 2014/15, in line with the Government's approach. The payment would not be increased from the 2013/14 payment level, as it was already significantly greater than the Government's level of payment.

It was noted that in advance of the Winter Fuel payment being made, beneficiaries would be asked to update their bank details information. However, as in 2013/14 people would not be asked to complete a Part 2 census form in order to receive the winter fuel payment.

[GRO-A] felt that carers were not adequately supported by Caxton, eg because it took too long to get a decision on respite breaks through the NWC. [GRO-A] suggested that carers be given an

annual payment so that they could make decisions about respite breaks without recourse to NWC. AL agreed to ask NWC to look again at carers.

It was agreed to clarify the meaning of a clause in the Trust Deed relating to primary beneficiaries which GW cited at the meeting.

In response to a question from [GRO:AL] regarding when the office guidelines would be made public, JB advised that it have never been the intention to do this. This was because office guideline limits were indicators for staff, not maximum grant amounts.

4. Regular payments system

AL advised that the Caxton board had been concerned by the number of beneficiaries who applied for grants who were on very low incomes and wanted to find a way to support people who were in this situation. The board had wanted to introduce a regular payments scheme for beneficiaries on the lowest incomes, and to top up their incomes to 80% of the median income. The organisation had submitted a business case for additional funding to set up a regular payments scheme to the Department of Health before Christmas; this had been turned down. In light of this decision, the board had reviewed what it was able to do to support those in the greatest financial need with a more limited budget. The board was mindful in doing this that it did not want to reduce the budget for grants.

JB explained the changes to the revised regular payments scheme. The key principle of the scheme was to support those who were on the lowest incomes. Caxton was keen to ensure that the scheme was based on an externally recognised measure of poverty/low income, and in needing to revise the scheme to make it feasible within the limited budget, had chosen the marker of 60% median income which is the official "poverty line". The cost to 'top up' beneficiaries' income to 80% of median income, which was the original proposal, would have been £3.5million, whereas the revised scheme had to work within a budget of around £800,000, less than a quarter of what had been requested. The board therefore had focused on supporting those below 60% median income, but unfortunately would not be able to make incomes up to this level, instead will only be able to make a limited regular payment to those falling below the poverty line. This was less than the organisation wanted to do, but all that was feasible from the limited budget.

Caxton would be writing to all beneficiaries at the end of August/beginning of September to set out details of the planned scheme and to invite those who want to be considered for support to complete a detailed "census" form to allow Caxton to establish whether they would be eligible for a payment.

In response to questions JB confirmed that the financial definition of the poverty line was different, dependent upon the numbers of adults and children in the household, and reflected the fact that households with more members had higher costs.

5. Funeral Plans and Bereavement Grants

In response to a question from GW regarding why only primary beneficiaries in receipt of Stage Two Skipton Fund payments could receive grants for funeral plans, JB advised that one of the principles Caxton operated on was that it should not do something for one person that it could not do for someone else in the same situation. Caxton had calculated that it would cost more than its

annual allocation to pay for funeral plans for everyone, and therefore had to prioritise funeral plans for those at Stage Two. However, JB advised that for all other beneficiaries, funeral costs could be met through bereavements grants at the time of bereavement.

It was agreed that this would be clarified on the Caxton website.

6. Beneficiary Communication Survey

VP reported back on the beneficiary communication survey which had been sent to all Caxton beneficiaries in July. There had been a very high response rate of 57% to the questionnaire which asked what type of communication methods people preferred from Caxton and what information they would like to receive.

Types of Communication:

There was an overwhelming interest in receiving newsletters, either by post or email, with 96% of responders selecting a newsletter of one type or the other. There had been quite a lot of interest in the website updates although there were also a number of comments that people were concerned that all communication would go 'online' and they would prefer information through the post.

There was very little interest in attending regional meetings, with just 16% of the beneficiary population showing an interest in attending regional meetings.

Information to be Communicated:

There were four options for this, updates from Caxton on grants and news, information on benefits and what is available, information on other organisations which may be able to support beneficiaries or information on new treatment for Hepatitis C. The responses to this were evenly split with interest in all four areas. Comparatively, there was slightly less interest in information about new treatments, but this may be a reflection of the number of widows who completed the form who would not necessarily have an interest in this.

VP went on to explain the board were meeting on the 7th August to consider the results of the survey. Work had already started on updating the information about Caxton and the grants scheme on the website and this would be completed to reflect feedback from the survey and some of the suggestions from the Partnership Group meeting. It was being recommended to the board that Caxton pilot a newsletter; the board would also consider whether to proceed with regional meetings given a lack of interest in them.

There was feeling in the group that there could have been a broader selection of questions asked, for example eliciting feedback on the services offered. AL confirmed that the survey had been focused on communications with beneficiaries and that feedback from beneficiaries was something that would be looked at later in the year.

The group was keen to pursue a meeting for beneficiaries, regionally or nationally but it was stressed that this would not be cost-effective given the low interest expressed.

6. Partnership Group

JB outlined what had been in the paper circulated to members before the meeting. The Partnership Group had been a useful forum to start developing communications with the organisation's stakeholders and had proved useful in obtaining views and feedback from those attending. The

organisation wanted to engage better with its beneficiaries and had been doing some work to better understand the demographics of its beneficiary group. In this review it had become clear that the current composition of the Partnership Group did not fully reflect the beneficiary community in full.

Caxton therefore intended to broaden the stakeholders on the Partnership Group to better reflect the beneficiary community to include more primary beneficiaries, both male and female and those with Haemophilia and without, widows and carers. The representation from campaign groups would also reduce from two to one per group although JB stressed that attendance from each group could rotate so that if someone was unable to attend they could still send a representative to the group.

Representatives from other organisations were discussed and it was agreed that the CEO of the Hepatitis C trust be approached and asked to send a representative if he was unable to attend future meetings.

JB confirmed that beneficiaries would now be asked to express an interest in being part of the group.

Following a question from [GRO-A], JB confirmed that many group members were here as both beneficiaries and members of campaign groups and would need to be clear in which category they were attending at future meetings.

There was some discussion about the definition of a "campaigner" and agreement that the board members of the campaign groups and those most active in the groups would be considered "campaigners".

There was discussion in the group regarding the purpose of the Partnership Group and whether there was a role for the members to be consulted outside of the meetings. JB stressed that sometimes ideas discussed at the Partnership Group needed further consideration, for example the concept of beneficiary meetings had been discussed at the Partnership Group meeting but on consulting the wider beneficiary group there was not much interest.

7. Any other business

The issue of referrals to the money management advisor was raised.

[GRO-A] asked what would happen if someone was referred for a second time and refused. JB advised that this had not yet happened, but each case would be looked at individually based on the beneficiary's individual circumstances.

There was discussion regarding whether someone could obtain their own money management advice independently of the Caxton money management advisors. It was noted that people could and did choose to do this. However, if someone was to make a request for debts to be paid off by Caxton it would still need to see some evidence of what advice had been given to inform their grant making decisions.

GW raised concerns that the meeting was not long enough to go through all the points he had to raise and asked for longer meetings to be considered in future.

8. Date of the next meeting

Autumn 2014

Action points

1. Action points would be included in future minutes
2. AL to advise Caxton board of [GRO-A]'s suggestion to have someone with haemophilia and experience of living on benefits on the board
3. A copy of the business case presented to the Department of Health before Christmas would be shared with the Partnership Group
4. Clarification on wording regarding primary beneficiaries in the Caxton Trust Deed
5. The NWC would be asked to review support that is available for carers
6. The Haemophilia society would liaise with Caxton to arrange for Caxton FAQs to be available on the Haemophilia Society website
7. The content of the Caxton Website and grant applications will be reviewed to include clarity on grants available for Funeral plans and bereavement costs