

## **The Caxton Foundation**

### **Partnership Group**

Notes of a meeting of the Caxton Foundation Partnership Group held at 2pm on 6 November 2014 at National Council for Voluntary Organisations, 8 All Saints Street, London N1 9RL.

**Present:** Charles Lister - Vice Chair, Caxton Foundation  
Jan Barlow – Chief Executive, Caxton Foundation (and the Macfarlane Trust)  
Victoria Prouse – Director of Operations, Caxton Foundation  
Margaret Kennedy – Board member, Caxton Foundation  
David Fielding – Manor House Group  
Glenn Wilkinson – Contaminated Blood Campaign  
Harold Brisley  
Jackie Britton  
Norman Hutchinson  
Claire Pinn  
Jacqueline Wratten

**Apologies:** Ann Lloyd, Chair, Caxton Foundation  
Richard Finlay, Board member, Caxton Foundation, and Chair of NWC  
Representative from Tainted Blood

#### **1. Welcome and introductions**

CL welcomed everyone to the first meeting of the Partnership Group with the new beneficiary members attending. He advised that after a year of running the Group, Caxton had been keen to expand the membership to make it more reflective of the beneficiary community as a whole, not just campaigners, and to get views from a broader cross-section of beneficiaries (primary beneficiaries, widows and widowers, and carers). Everyone introduced themselves; several of the new members of the Group said that they had found Caxton very helpful when they had approached the organisation for support.

There was a discussion as to whether one member of the Group could record the meeting. It was agreed that he could, on condition that all names be anonymised on any transcript that was produced subsequently. This was in recognition of the fact that some beneficiary members may not wish to have their Hepatitis C status disclosed, and that not attributing comments or opinions to individual would ensure that everyone felt free to speak their mind.

Following questions, JB explained to the Group about the other organisations within Alliance House, including their different histories, and about the small staff team which supports all 5 organisations.

#### **2. Ground Rules and Terms of Reference**

CL said that it was normal practice for a group such as this to have ground rules for how it would operate and how meetings would be conducted. He read out the key areas, which people agreed were reasonable. It was agreed that the ground rules document would be circulated to all members of the Group outside of the meeting.

The Group then considered the proposed Terms of Reference for the newly-constituted Group.

Concern was expressed that other organisations were no longer going to be part of the Group. CL explained that the Haemophilia Society and Hepatitis C Trust had been invited to previous meetings

from the beginning, although no one from the latter had been able to attend. Recently, Caxton had been approached by Haemophilia Scotland and the Scottish Infected Blood Forum also asking to join the Group. Caxton was keen that the Partnership Group should be a forum primarily for discussing its work with beneficiaries, particularly now that a broader sub-section of beneficiaries were members. Having a growing number of organisations as part of the Group would inevitably reduce the focus on issues directly affecting beneficiaries. Caxton had therefore decided to meet separately once a year with the other charities to discuss more strategic issues. In response to a criticism that there was no point having a Partnership Group meeting because it was the Caxton board which made decisions, CL explained that the Partnership Group provided an opportunity for beneficiaries to share their thoughts and feedback about Caxton's work. These views were fed back to the Board. However, the Caxton board was an independent body which had to make decisions based on a range of evidence.

One member questioned, CL's position on the Caxton board, given he had previously worked within the blood policy team at the Department of Health (1999-2003). JB explained the standard procedure for recruitment of board members, including the fact that boards need to have a range of relevant skills for running their particular organisation, including legal, finance and HR skills. For a health charity such as Caxton, it would be expected to have board members with a health/health policy background. JB stressed that CL had worked in the blood policy team a long time after the contaminated blood scandal took place. There was therefore no conflict of interest.

Following discussion around the number of meetings in a year, the issue of having either one large beneficiary event or smaller events was raised. It was reiterated that a survey had been sent to all beneficiaries in the summer, which showed that there was not enough interest in such meetings to justify holding them, including on the grounds of cost. However, it had been agreed, and noted at the August meeting, that this would be reviewed again in a year's time.

CL said that, for future meetings, Partnership Group members would have an opportunity to suggest agenda items. This has not happened on this occasion due to the large amount of business on the agenda.

The Terms of Reference were agreed, subject to one change regarding the recording of meetings.

### **3. Minutes of the last meeting**

The minutes of the meeting held on 5 August 2014 had been circulated with the agenda and were agreed as a correct record.

### **4. Matters arising and updates**

- i) **AL to advise Caxton Board of suggestions to have someone with haemophilia and experience of living on benefits on the board** - CL advised that this had been discussed at the board but at the current time Caxton was not looking to recruit any new board members.
- ii) **A copy of the business case present to the Department of Health before Christmas would be shared with the Partnership Group** - CL confirmed this had been circulated to members of the Group in August.
- iii) **Clarification on wording regarding primary beneficiaries in the Caxton Trust Deed** - JB confirmed that she had written to GW after the meeting in August. JB agreed to resend it to GW as he said he had not received it.

- iv) **NWC would be asked to review support that is available for carers** - CL advised that the NWC had reviewed this and had now delegated consideration of all routine requests for respite breaks to the office. This meant that routine applications would not need to be presented to the 6-weekly NWC meetings but could be processed more quickly through the office. Following questions about how long and where respite breaks could be agreed for, JB confirmed that there were no specific criteria in that respect, and a beneficiary could apply for a break of their choosing. However when considering respite breaks, charitable need would need to be demonstrated.

There was a discussion around the rules relating to retrospective grants. JB confirmed that retrospective grants were not considered other than in exceptional circumstances as it was hard to demonstrate charitable need if an item had already been purchased.

## **5. Caxton Beneficiary numbers**

CL informed the Group that the Skipton Fund had been asked by the Department of Health to attempt to contact everyone in England who had ever received a Stage 1 payment but with whom there had been no subsequent contact, in order to understand the number of people who are still contactable. This had involved the Skipton Fund attempting to contact around 2000 people, a large proportion of whom had received their Stage 1 payment before the Caxton Foundation was established in 2011.

CL explained that this was not a piece of work that Caxton could have done itself, as for data protection reasons Caxton was not able to access the details of Skipton registrants unless individuals had expressly given Caxton permission to do so. Caxton was pleased that the Skipton exercise had identified so many more Caxton beneficiaries, and JB confirmed that there were 890 beneficiaries registered with Caxton as of the morning of the meeting and since the initial influx in September, numbers had continued to increase by approximately 2 a day. JB confirmed that when Caxton had been advised that this piece of work was going to be done, they contacted the Department of Health to find out what additional financial provision had been made for Caxton in the light of the increased beneficiary numbers that would arise. The Department of Health had advised that there would be no additional funding in year. Following questions regarding future beneficiary numbers, it was confirmed that the numbers were not likely to go down, as in many cases when a beneficiary passed away their widow/widower would then register with Caxton. It was noted that approximately 50% of Caxton primary beneficiaries had a bleeding disorder.

## **6. Winter fuel payment**

CL explained that the original budget for the winter fuel payments had been made on the assumption of an increase in beneficiary numbers, but not at the unexpectedly high level that had occurred as a result of the Skipton look-back exercise. The board had therefore had to review the 2014/15 budget. The board had not wanted to reduce the grants budget or the budget for the regular payment scheme. It therefore had to look at the level of the winter fuel payments and had made the difficult decision to reduce these to £350. The rationale was to direct spending towards beneficiaries on the lowest incomes.

## **7. Regular payments system**

JB advised that Caxton had been concerned about the number of beneficiaries applying for grants who were on very low incomes and had 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 low incomes and to be able to top up their incomes to 80% of median income; the poverty line is defined as 60% median income. Caxton had submitted a business case for additional funding to set up this scheme to the Department of Health towards the end of 2013. The Department had declined to fund this business case. In light of this decision, the board had reviewed what it was able to do to support those in the greatest financial need, and had therefore decided to introduce a more limited scheme from within its existing budget.

JB explained that the scheme had been designed to support those who were on the very 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". This was less than the organisation wanted to do, but all that was feasible with the limited budget. JB confirmed that the letters informing people of the scheme would be sent out on Friday 7 November 2014. As the scheme was new, it would be reviewed in the light of experiences of the first year.

In response to questions, JB confirmed that Caxton's Trust Deed did not limit Caxton to only making grants and did not prevent it from making regular payments. There was a discussion about the likelihood of receiving additional funding from the Department of Health mid way through the financial year. CL advised that funding was allocated by the Department at the start of each financial year, and so additional funds would not be forthcoming. There was discussion about the other work underway at the current time including by Alistair Burt MP, the All Party Parliamentary Group and the Penrose Inquiry and how these might affect the Department of Health's decision as to the level of funding available for Caxton and when any decisions would be made. The potential impact of the May 2015 General Election on the timing of announcements and decisions was also discussed.

Following concerns that Caxton might be in a difficult position asking for additional funding from the Department of Health, CL stressed that the fact that the Department of Health was Caxton's sole funder did not inhibit Caxton from submitting business cases and requesting additional funding.

The Group discussed the new treatment for Hepatitis C and how NICE was yet to announce their decision as to whether they would recommend that it be made widely available. Following questions about whether Caxton would be able to fund beneficiaries to have the new treatment if NICE did not recommend it on cost effectiveness grounds, JB explained 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's limited funding meant that it would cost Caxton's entire annual allocation to pay for approximately only 40 people to have treatment per year, and it would be able to provide no other support whatsoever to the rest of its beneficiary community, ie no grants, winter fuel payments, regular payments etc. It was therefore not financially feasible for Caxton to fund beneficiaries to have the new treatment. It was suggested that Caxton could submit a business case requesting additional funding to pay for treatment for all beneficiaries. JB explained that the Department of Health controlled the funding for both Caxton and the NHS. It was therefore highly unlikely, if one part of the Department had decided that money was not being made available widely to the NHS for these treatments on cost-effectiveness grounds, that another part of the Department would agree that money be provided to Caxton for the same purpose.

## **8. Any other business**

A question was raised as to how the member of the one of the campaign groups who is a carer would canvas the views of other carers. It was reiterated that the beneficiary members of the Partnership Group were not there as representatives, but to be reflective of the wider Caxton beneficiary community. People were therefore not expected to canvass the views of other beneficiaries, and

some of the new members of the Group felt that they would not be able to do this anyway. However, there was nothing to prevent members of the Group making wider contacts if they wished to do so.

The location of meetings was discussed as one member felt that London was too far for people to travel. JB explained that with the new members of the Group coming from more far reaching parts of the UK, including the south coast, North Wales and Scotland, London had the best transport links for all members. The general consensus from those attending was that London was the most practical location, but it was agreed to ask members in advance of the next meeting whether they would prefer to meet in London or Birmingham.

Following a question about funeral plans, JB advised that the board had reviewed this previously and reiterated the position explained at the last Partnership Group meeting, namely that it was not financially possible to provide funeral plans to all beneficiaries and so these were only available to primary beneficiaries in receipt of Skipton Stage 2 payments. However, bereavement grants were available for other beneficiaries at the time of a bereavement.

Following a question regarding the level of the Chief Executive's salary, JB advised that it was a matter of public record for all charities what the remuneration costs of certain staff were, and this information was published in the annual accounts. It was confirmed that the figures were total costs and not the take home salary for the individual member of staff.

In response to a question as to whether the Office Guidelines would be published, CL reiterated again that they would not be published because they were the level at which the board had delegated powers to agree grants through the office, to decrease the number of grants which have to wait for committee to be considered, they were not upper limits for grants overall.

Further to a request that publicity about the campaign organisations and their work be included in the Caxton Newsletter, JB advised that this would be put to the board for a decision.

## **8. Date of the next meeting**

Spring 2015

## **Action points**

1. Caxton to circulate the ground rules for meetings.
2. Resend letter to GW re Trust Deed.
3. Caxton to ask members whether they would prefer meetings to be held in London or Birmingham before the next meeting was organised.
4. Caxton to consider whether to publicise the campaign groups in the Caxton newsletter.