

## The Caxton Foundation

### Partnership Group

Notes of a meeting of the Caxton Foundation Partnership Group held at 2pm on 25 November 2015 at National Council for Voluntary Organisations, 8 All Saints Street, London N1 9RL.

**Present:** Chris Pond – Chair, Caxton Foundation  
Jan Barlow – Chief Executive, Caxton Foundation  
Victoria Prouse – Director of Operations, Caxton Foundation  
David Atterbury Thomas – Board member, Caxton Foundation  
David Tonkin – Manor House Group  
David Fielding – Contaminated Blood Campaign  
Jacqueline Wratten  
Jackie Britton  
Norman Hutchinson  
Harold Brisley  
Matthew Johnson

**Apologies:** Claire Pinn

#### 1. Welcome and introductions

CP welcomed everyone to the meeting and everyone introduced themselves.

#### 2. Ground rules

CP noted the ground rules as agreed at the previous meeting.

#### 3. Minutes of the last meeting

The minutes of the meeting held on 6 November 2014 had been circulated following the meeting, and again with the agenda for today's meeting, and were agreed as a correct record.

#### 4. Matters arising

- i). **Caxton to circulate the ground rules** – this was done after the last meeting, on 25 November 2014.
- ii). **Agenda items** - A member raised the point that it had been agreed previously that members of the group would be asked to submit agenda items if they wished. VP confirmed that this had been done on this occasion and that she had received some suggestions which had been incorporated into the agenda.
- iii). **Business Case** – it was noted by a member of the group that in the matters arising from the minutes of the meeting of 6 August 2014, reference had been made to a business case being sent to the members of the group at the time, and asked if this year's business case could also be sent to the group. JB confirmed that the business case in question related to a request for additional funding for the regular payments scheme which had been submitted to the Department of Health in late 2013. JB confirmed that business cases were not necessarily submitted annually, so there was no new case to send to the group.
- iv). **Campaign organisations being allowed to advertise in the Caxton newsletter** – The issue of whether campaign groups' contact details could be put in Caxton newsletters had been discussed at the board meeting in December. The board had felt that this would be inappropriate and therefore did not agree to do this. The member of the group who had raised this last November had been informed of this by email after the meeting. In response

to further questions from one member of the group, CP stressed that Caxton was not a campaigning organisation and that its role and remit were different from those of the campaigning organisations.

## **5. Caxton update**

### **A. Changes to the Caxton Board**

During his introduction, CP advised the group that Ann Lloyd had stepped down as Chair of Caxton in March 2015 and that he had been appointed in July 2015.

### **B. Beneficiary Numbers**

JB informed the group that beneficiary numbers continued to increase, but not at the level which Caxton had seen following the Skipton look-back exercise in 2014. Beneficiary numbers as at the end of October 2015 were 1142, an increase of 6% since 1 April 2015.

### **C. Communication with beneficiaries**

JB confirmed that following the communications survey in 2014, Caxton had introduced a newsletter: one had been sent in December 2014, another in July 2015.

Following discussion it was agreed that Caxton would include information in the next newsletter regarding the bereavement grant available from Caxton, and the winter fuel payments which are available from the government for those of pensionable age. It was also agreed to repeat the messages from the previous newsletter regarding assistance that beneficiaries could apply for during treatment for Hepatitis C.

The group also discussed the use of the website and whether this, or other sites, were the best place to get up to date accurate information with regard to political developments. One member explained that they were on the mailing list for the All Party Parliamentary Group for Haemophilia and Contaminated Blood and received their updates.

JB explained that Caxton had updated beneficiaries with any information it had about political developments in the newsletters.

It was agreed that Caxton would review the news and links part of the website and post the newsletters on the website.

### **D. Winter fuel payment**

JB confirmed that Caxton would be making a £500 winter fuel payment for all primary beneficiary and bereaved spouse/partner households for 2015/16. She advised that all eligible beneficiaries had been asked to complete a bank details form to ensure that their details were up-to-date. The deadline to return the form was 30 November 2015 and Caxton was aiming to make the payment in December to those who had returned the form by the deadline. CP reiterated that Caxton would still make payments to beneficiaries who returned their forms after the deadline, but these would be made at a later date.

JB informed the group that Caxton was aware that Shona Robison, the Scottish Cabinet Secretary for Health, Wellbeing and Sport, had written to Jane Ellison MP earlier in the year to suggest that some of the £25 million announced by David Cameron in his March statement to the House of Commons should be distributed by way of an increased winter fuel payment to Caxton Foundation beneficiaries. JB advised that Caxton was not aware of any decision in relation to this suggestion and had received no additional funding for winter fuel payments in 2015/16.

A member of the group asked whether beneficiaries could be informed earlier in the year whether Caxton would be making a winter fuel payment. CP advised that whilst Caxton would

like to be able to do this, it was not possible for budgetary reasons, as it was only at the November board meeting that Caxton could assess how much the payment could be. JB added that Caxton was not allowed by the Department of Health to accumulate reserves and it could not spend more than its annual allocation. It therefore had to monitor spend carefully and not commit to payments it could not afford to make.

Following a discussion about Caxton's role in canvassing for more income for the organisation, JB confirmed that Caxton does lobby the Department of Health for additional funding, but in the light of the Government's Spending Review and the forthcoming consultation about future arrangements, additional funding at the current time was unlikely.

#### **E. Grants**

JB explained that grants continued to be one of the major ways Caxton supported beneficiaries. Over the last 12 months, the board and the National Welfare Committee (NWC) had continued to ensure that as many applications as possible could be processed under Office Guidelines and therefore dealt with quickly through the office without need to wait for the 6 weekly NWC meetings. The turnaround times for Office grants, from the point at which the office received the required paperwork, was now an average of 2 days, and 9 days on average for grants that go to NWC.

A member of the group asked if Caxton could publish a list of all grants applied for and the outcome, by grant type. This led to a wider discussion about grants, during which the majority of the group said that they had been happy with the response they had received from Caxton when they had applied for grants.

In relation to retrospective grants, JB confirmed that some had been agreed when Caxton was first set up, as the board had been aware that people had not previously been able to access charitable support. However, now that the organisation was established, beneficiaries had been made aware that they needed to contact the organisation at the time of need rather than at a later date after the item/work had been purchased and paid for. JB explained that the organisation needed to determine charitable need when assessing grants and it was difficult to do this when an item had already been paid for.

The group discussed the support available to spouses if a primary beneficiary passed away. It was confirmed that Skipton Fund Stage Two payments were paid up until the end of the quarter in which the person passed away, even for those on monthly payments. The bereaved spouse/partner could then register with Caxton to receive support towards bereavement costs and other support in their own right. Members of the group stated that they were pleased that Caxton was there to support bereaved spouses and partners as they were not supported by the Skipton Fund. Additional support for them was something that had been campaigned for prior to Caxton being set up and this was seen as an important group of people for Caxton to support.

#### **F. Regular Payments Scheme**

JB informed the group that the regular payments scheme had continued to run in the current financial year. The scheme was open to any new beneficiaries who wished to apply, or any existing beneficiaries whose circumstances had changed and who were now eligible for the scheme. JB advised that in 2014/15, 19% of primary beneficiaries and bereaved spouses/partners had received support via the scheme. JB confirmed that Caxton was not in a position at the moment to confirm if they would have the resources to run the scheme in 2016/17, although it would hope to do so. Beneficiaries in receipt of the payments had been informed of this and would be kept informed when Caxton knew what funding it had available for 2016/17.

There was a discussion regarding the eligibility level of the regular payments scheme, what support was available to beneficiaries through benefits, and about the inclusion of the Skipton Fund regular payments as part of household income. JB confirmed that Caxton had had to introduce a very limited scheme because of the lack of additional Department of Health funding, and had had to target the scheme at those on the very lowest incomes and assess people's absolute income. JB confirmed that the current level of eligibility had been set at 70% median income (what is commonly known as the "poverty line" was 60% median income).

JB confirmed that beneficiaries who were not eligible for Caxton regular payments were still able to apply for grants, as each grant was considered on a case by case basis. JB confirmed that beneficiaries who were not eligible had been advised that they could still apply for grants and Caxton would continue to reiterate this.

## **6. Political Developments**

JB highlighted the political developments since the last Partnership Group meeting in November 2014:

### **APPG report**

The APPG on Haemophilia and Contaminated Blood had published its report in January 2015.

### **Penrose Enquiry**

The Penrose Inquiry report had been launched on 25 March 2015. The report had only made one recommendation, that everyone in Scotland who had a blood transfusion before 1991 should be tested for Hepatitis C.

### **Apology and Announcement from Prime Minister and Scottish Government**

Following the launch of the Penrose Inquiry report, the Prime Minister made an apology during Prime Minister's Questions on 25 March 2015. He also announced an additional, up to, £25 million in 2015/16 to support any transitional arrangements to a better payment system. The Scottish First minister, Nicola Sturgeon MSP and the Cabinet Secretary for Health, Wellbeing and Sport, Shona Robison MSP, had also made formal apologies on 26 March 2015 to the families and individuals affected by contaminated blood in Scotland.

JB confirmed that to date, Caxton had not been informed of how or when this additional £25 million would be spent and how much, if any, would be given to Caxton for additional support for beneficiaries.

### **Statement to Parliament**

Jane Ellison MP, Under Secretary of State for Public Health, had made a written statement to the House of Commons on 20 July 2015. The statement confirmed that the £25 million announced by David Cameron would not be used for administrative purposes but would be used for supporting transitional arrangements, once a consultation on future arrangements had taken place.

Following this, Ben Gummer MP, Parliamentary Under Secretary of State for Health, had made an oral statement in the House of Commons. He confirmed that a consultation would be taking place in the autumn and that a decision regarding any changes that may take place would be announced before the end of the financial year.

### **Westminster Hall Debate**

There had been a short Westminster Hall debate on contaminated blood on 9 September 2015, brought by Margaret Ritchie MP. During the debate the Minister, Jane Ellison, stated that:

- Consultation would take place before the end of the year

- The provision of future financial assistance was being considered in the context of the Spending Review and in a way that was sustainable for the future
- The Government was hoping for a UK wide approach along with the devolved administrations
- The £25 million announced in March, if not spent this year, would be carried forward into 2016/17
- Liability had not been established in the majority of cases, so they were not talking about payments in terms of compensation and not on the scale that some people envisaged.

#### **Consultation on future arrangements**

JB advised that Caxton did not have any further information regarding when any DH consultation would take place and what form it was expected to take.

#### **Scottish Review Group**

Following the publication of the Penrose Inquiry Report, the Scottish Health and Social Care Department had set up a Review Group to look at the financial support schemes for those infected with HIV and Hepatitis C as a result of contaminated blood in Scotland and had consulted with the infected community in Scotland through a series of regional meetings, a survey and one to one meetings. The group had recently published its draft recommendations.

Members of the group discussed some of the developments and their frustration with the time taken for any changes or consultation to take place. The group also fed in their understanding of progress made to date, possible outcomes to the consultation and the proposals being made in Scotland. There was also a discussion regarding where funding for future support might come from and how cases had been made to the Department of Health and Ministers that it should come from the Treasury and not the Department of Health's existing budget.

CP confirmed that these decision were outside of the control or remit of Caxton, but confirmed that it was useful for the organisation to hear the group's diverse views.

### **7. Any Other Business**

One of the members asked about the separate meeting for organisations and whether this was something specifically for Scotland. JB explained that the Haemophilia Society and Hepatitis C Trust had been invited to the original Partnership Group, although no one from the latter had been able to attend. Caxton had subsequently been approached by Haemophilia Scotland and the Scottish Infected Blood Forum also asking to join the original group. Caxton was keen that the Partnership Group should be a forum primarily for discussing its work with beneficiaries, and had therefore decided to meet separately once a year with the other organisations to discuss more strategic issues.

Caxton agreed that the campaigning organisations could choose to attend the organisations' group instead of the Partnership Group if they wished. JB explained that the meeting with the organisations would probably not involve such detail about Caxton's work. The Manor House representative asked if they could attend a meeting of the organisations' group to enable them to decide which forum would be best suited to their involvement. This was agreed.

A member of the group asked if the Partnership Group could have a meeting with all the Caxton board. CP noted that board members had attended today's meeting and previous meetings and that information would be fed back to the board. CP advised that in light of the current uncertainty regarding the future support structure, a meeting with the board at the current time would not necessarily be helpful, as the structure may change. He therefore suggested that this request be reviewed again when it was known what, if any, changes to the structure were to be put in place.

In response to a question as to whether the staff of Caxton were civil servants, JB confirmed this was not the case and that they were all directly employed by Caxton, an independent charity.

In response to a question regarding the advertising of board member vacancies, CP explained that the appointment of any new board members would be reviewed when the structure of any future support had been decided.

A member of the group noted that previously the CBC attendee had recorded the meeting and provided their own minutes/transcript. Caxton confirmed that, as discussed at the last meeting, it had been agreed by the group that they were happy for the meeting to be recorded, as long as no comments were directly attributed to individuals. Caxton confirmed that they would continue to provide minutes of the meetings which would be circulated to the group and made available on the Caxton website.

**8. Date of the next meeting**

Spring 2015

Further to a request from a member to have meetings in warmer months, it was agreed to consider a meeting in spring and then in late summer.

**Action points**

1. Caxton to post the newsletters on the website and to review the news and links page to ensure the links are all working.
2. Caxton to include information regarding winter fuel payments, bereavement grants and financial assistance available whilst undergoing treatment in the next newsletter.
3. Caxton to review the timings of the meetings to avoid the colder winter months.