

Witness Name: Glenn Wilkinson

Statement No.: WITN2050001

Exhibits: WITN2050002 – WITN2050114

Dated: 14 August 2020

**INFECTED BLOOD INQUIRY**

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**EXHIBIT WITN2050095**

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## **The Caxton Foundation**

### **Partnership Group**

Notes of a meeting of the Caxton Foundation Partnership Group held on 11 June 2013 at the National Council for Voluntary Organisations, 8 All Saints Street, London N1 9RL.

**Present:** Ann Lloyd - Chair of the Caxton Foundation  
Charles Lister - Vice Chair of the Caxton Foundation and Chair of the National Welfare Committee  
Jan Barlow – Chief Executive of the Caxton Foundation (and the Macfarlane Trust)  
Chris James - Chief Executive, the Haemophilia Society  
GRO-A – Manor House Group  
GRO-A – Manor House Group  
GRO-A – Tainted Blood  
GRO-A – Contaminated Blood Campaign  
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GRO-A – Tainted Blood  
Glenn Wilkinson – Contaminated Blood Campaign

**Apologies:** Charles Gore – Chief Executive, Hepatitis C Trust

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

AL welcomed everyone to the meeting and everyone introduced themselves and explained a little about the background to their involvement in their respective organisations.

AL advised that she wanted the Partnership Group to help Caxton develop policy and strategy for the future. When she had been appointed Chair earlier in the year, she had reviewed what the organisation was doing and in discussion with others had concluded that there were a number of things which weren't working as they should. There were areas where a better service could be provided for clients, and there was a need for improved dialogue between the Foundation and clients. She felt it was important to acknowledge the many larger campaigning issues which clients and the campaigning groups were involved in, but to be clear that Caxton itself had not been set up as a campaigning organisation. Caxton would also not give priority to one sub-group of its clients over another. AL advised that the board had begun the process of developing a strategy, and there was a focus on raising awareness of Caxton and reaching clients who had not yet registered with the organisation. She emphasised that progress was already being made, in some areas in direct response to concerns raised by clients and the Health Minister, for example in now giving people the choice of having grants paid directly to them, instead of either via vouchers or directly to suppliers, although a number of safeguards had had to be put in place in support of this new approach.

#### **2. Caxton Partnership Group**

AL advised that Caxton wished the Partnership Group to help make the organisation more effective in supporting its clients and developing its services. There was some discussion regarding the composition of the group. It was agreed that the main group should be more inclusive, and include people who had haemophilia as well as those who did not, and also include primary beneficiaries, widows, and carers. After discussion it was agreed that the main PG should meet twice a year. It

was also agreed that there should be a wider forum to which all beneficiaries could be invited; this could be convened once a year.

The issue of identifying additional beneficiaries was raised. AL advised that the intention would be to advertise through patient groups such as the Patients Association; other suggestions were charities which supported carers and also through articles in national newspapers, which JB confirmed was already under consideration. CJ also offered to print an article in the Haemophilia Society newsletter. JB advised that at the time Caxton was set up, the Department of Health had undertaken an exercise to promote the charity through NHS organisations, with limited success. Overall, raising awareness to those who may be eligible for support from Caxton was complicated by the fact that people had to have received a Stage 1 Skipton Fund payment before they could register with Caxton, and that Skipton could not share information about their beneficiaries with Caxton without their beneficiaries' consent.

### **3. Current topics**

#### **3.1 Caxton legal status**

Concerns had been raised by one of the campaign groups regarding the legal status of the Caxton board. JB explained that in 2012, the decision had been taken to incorporate the board of the Caxton Foundation (ie make it a limited company) to address individual trustee liability concerns. This was not the usual model where charities often had full dual registration with the Charity Commission and Companies House, in which cases the trustee board had the same members as the company board of directors, and the individuals operated in a dual capacity. For Caxton, this meant that technically the charity only had one trustee, Caxton Trustee Ltd, which was the corporate trustee; it was therefore technically incorrect to refer to the board members as trustees, although within the organisation the term "trustee" to refer to board members was used colloquially. When the incorporation had taken place last year, there had been some administrative oversight and Caxton had not registered Caxton Trustee Ltd as the new corporate trustee. JB had now rectified this.

AL advised that the board planned to work with the Hepatitis C Trust to recruit an additional board member who had experience of living with Hepatitis C. Concern was raised that the Hepatitis C Trust did not represent people with haemophilia. AL and CL agreed to look into this.

#### **3.2 Caxton's support to clients**

AL referred to the work that the board of Caxton had done to start developing a strategy. As part of this work, a vision and mission had been developed, together with some strategic principles:

**Vision:** Caxton wants everyone who has been affected by Hepatitis C derived from the NHS to be able to live a positive, fulfilling and independent life.

**Mission:** We will reach out to all those affected by Hepatitis C derived from the NHS and work with them to improve the quality of their lives.

**Strategic principles:**

- Effective identification of beneficiaries and effective communication and awareness raising
- Effective intervention
- Understanding the external environment

- Ensuring we are appropriately resourced

### 3.3 Other issues

**Grant application process:** The issue of the length of time it took to process applications was raised. CL advised that the National Welfare Committee (NWC) currently met every 6 weeks to consider grant applications. There was also a process in place whereby staff could approve some applications up to certain financial limits, as well as there being a process by which the NWC could approve urgent applications between meetings. CL acknowledged that not everything was working effectively yet, and JB also acknowledged that improvements to customer care were needed, which she was working to address. JB also advised that she was looking into whether it was possible to put details of the application process and relevant forms on the website.

**Means testing:** The issue of whether or not Caxton applied a £14,000 poverty threshold was raised, as information on the website suggested that it did. JB advised that when Caxton was first set up, because it was not clear how many people would come forward for support, this threshold had been used. However, in practice it had not proved necessary to apply this. When JB had started as Chief Executive, she had questioned why Caxton needed detailed financial information from everyone if payments such as the winter fuel payment were not means-tested. Caxton would therefore be moving away from asking for detailed financial information in terms of an annual census, although it would continue to request income and expenditure information in relation to grant applications. Having this information had enabled the organisation to provide more holistic support to people, particularly where there were issues with eg debts, which might not have been highlighted otherwise.

**Regular payment:** CL advised that there were a number of people who made applications to NWC who were clearly struggling financially from one month to the next. Consideration was being given to how some form of time-limited regular support could be introduced. JB stressed that this would not be a replication of the Macfarlane Trust discretionary regular payments system, which some of the meeting attendees were familiar with.

**Office guidelines:** GW asked whether the current Office Guidelines could be published on the website. CL said it would not be appropriate to do this, as the OGs only related to those things which the staff team could authorise without reference to the NWC, and they would therefore be misleading. However, consideration could be given to outlining the types of support that could be given.

**Financial support whilst on treatment:** GW asked what the situation was regarding payments for people whilst on treatment. CL advised that £750 was the average monthly figure which had been awarded, but that it was not fixed, and people's individual circumstances were taken into account in its calculation. The overall objective with these payments was that people should not be deterred from undergoing treatment by financial considerations. Questions were raised about the ongoing support to people who had been cleared of the virus; any such requests would be reviewed by the Welfare Committee.

#### **Communication and timescales**

Concern was expressed about the slowness of the application process and the general absence of communication. AL informed the meeting that the board was very concerned about this and had

asked JB to review the office's processes with a view to effecting a considerable improvement. This she had done; the report was currently under consideration by the board.

**4. Communication/client identification**

AL asked those present to help Caxton by identifying individuals who could benefit from their grants etc within their clients groups for ideas on the most effective ways in which to communicate with their clients. This would be discussed at the next meeting.

**5. Date of the next meeting**

PG - November 2013, exact date to be confirmed. Wider forum, January 2014.