

**Minutes of a Meeting held at the Department of Health, Wellington House
on Tuesday 28th June 2011
regarding the setting up of the Caxton Foundation**

Department of Health: Rowena Jecock (RJ)
Ailsa Wight (AW)
Ben Cole (BC)

MacFarlane Trust: Martin Harvey (MH)
Roger Evans (RE)
Rosamund Riley (RR)
Gillian Brown

1. Apologies

Apologies for late arrival were received from Martin Harvey and Ailsa Wight, and notification of early departure from the meeting was received from Rowena Jecock.

2. Brief Summary of Current Situation

A brief summary of the current situation was given by RE:

He relayed that the Trust Deed had been signed by all parties and that formal registration with the Charity Commission had been achieved. He also relayed that the formal business case was in the process of being constructed, covering proper governance issues and documents on probity and that everything was in hand.

He spoke of the situation regarding Trustee interviews and informed the meeting that of the 19 applications received, 8 had been invited for interview, mentioning that RJ would be familiar with a couple of the final 8. Overall, RE said that the standard of CVs received was good. He mentioned that the founder members of the Caxton Foundation (Caxton) were hoping to get a representative from each of Wales, Scotland and Ireland, but a Scottish representative was not so likely. RJ asked whether it was absolutely necessary to get wide representation from each country and RE said it was their intent to try and do so although it was not considered an essential criteria.

Finally, RE said that we were working towards having the Charity up and running by 1st October 2011.

RJ said that representation within the charity across the UK should not be a major concern and that the appointment of a Trustee should be made on merit, not on the geographical location of the interviewee; she reiterated that there was no indication from the DA that this should be a requirement.

RE said that Caxton should be able to demonstrate that we are equitable with MFT.

RJ said that when setting the policies for Caxton, account should be taken of the work of MFT and ET.

RE said that the onus was on applicants to show they are eligible for help from Caxton but he was sensitive to the possibility that applicants could face difficulties in obtaining the necessary clinical information through uncooperative doctors and medical agencies and suggested that some sort of appeal system was set up to deal with this.

RJ thought this was a good idea and expressed the view that it was going to be a more difficult process for Caxton than it was for the MFT and ET as there was much greater diversity of associated ill health attributable to Hep C; she suggested that as there was a large grey area where situations were not clear cut, we could implement case law as we go along.

She also felt that having a Trustee on board with this area of expertise would be most helpful, but not essential.

RE commented that if Caxton did not have this expertise in-house, Caxton would seek independent clinical expertise.

AW joined the meeting.

3. Office Matters

RE explained that MFT were currently on the 1st floor and hoping to move up to the 5th floor no later than September 2011.

MH joined the meeting.

RJ acknowledged that MH had been off sick for some time. She said that she saw no problem with the move in principle but felt that if the Business Case was not submitted fairly quickly this could jeopardise the move and cause Caxton to lose the option on the 5th floor and in turn cause a lot of knock-on problems for the operation of the charity.

AW felt that we had enough representation on the Board to help deal with this situation and reiterated the point about appointing a Trustee based on merit rather than geographical location. She also advised that arrangements for social care in Scotland were different to the rest of the UK and said it would be perfectly in order for Caxton to seek the advice of DH on these matters and they would be happy to provide the necessary factual information with regards to what is available in Ireland, Scotland and Wales.

4. Website

RE advised and RR confirmed that the website had been set up by Shane Baker and would be going live soon. RE said that he would appreciate any creative input from the DH to make it more attractive and interesting. AW agreed to explore website ideas with her son! She asked if there were automatic links to other websites.

RR reiterated that the website would soon be live and currently consisted of a welcome page requesting potential applicants to register their interest. Once submitted, their details will be added to a spreadsheet, which will be used to populate the database.

RR informed the meeting that at some point a census form would be designed and sent to those who have registered to help determine applicants' eligibility for help. This census form would ask for more detailed information on their circumstances, such as household make-up, income, health history and personal information. This information would help to populate the Caxton database with relevant information.

RE stressed the importance of getting the connection right for people who are eligible, whether it be electronically or through the post.

RE said that on MH's return to the office next week they would be working to finalise the Business Case.

5. Advertising

RJ felt that patient family support groups and the "grapevine" were the best ways of reaching most people.

AW said that the pre 2003 group would be difficult to locate as they are not in touch with centres, etc; there had been an estimate of over 1,000 possible applicants but only half that number have come forward to date.

RE said that Peter Stevens has estimated a potential figure of 3-4,000 applicants for Caxton.

MH mentioned that information on the creation of the Caxton had been put onto the Tainted Blood, Hep C, Haemophilic Society and Skipton Fund websites.

AW advised that the Manor House Group may be a point of contact for raising awareness of Caxton but RJ and BC were not sure if the Manor House Group's website was still in use.

AW suggested that half of the potential applicants would be non-haemophilic and that it would only be people with problems who would want to apply.

RE said it would be difficult to provide detailed information on the website before the funding levels and distribution thereof had been agreed.

AW suggested that in anticipation of any problems, arrangements should be reviewed at regular intervals, perhaps yearly. AW also felt that there needed to be more granular information on cases (such as the type of requests being received, what financial need is required and what other health issues may arise) and the necessity for stringent and accurate record keeping with a focus on the descriptions behind the figures. She also felt that there would need to be ample ammunition to support each case.

RE asked whether we should be taking this to the All Party Parliamentary Hepatology Group (APPHG).

RJ said that there was a Haemophilic one.

AW said that there was a Hep C one and Charles Gore was heavily involved in it as his charity acted as the Group's secretariat.

Both RJ and AW said that MPs ought to be going out into their constituencies and highlighting this issue.

MH said that anything to bring this matter to the fore would be most welcome.

AW said that any such publicity should be as cost-effective as possible. She also mentioned that Gerry Robb was well versed on blood borne viruses.

RE referred back to the website and expressed the view that the relationship between the Caxton and DH governance should be explained and that it should be ensured that the DH was not seen as part of the charity. RJ suggested that a simple and clear statement to explain the relationship between the two organisations should be added to the websites and this was agreed.

It was also suggested that RR could make enquiries to see if the Caxton website could come up if Hep C was entered into a search engine.

RJ said that the DAs were consulting their ministers and looking in particular at the Deed in principle rather than sorting out the details.

RE stated that the 3 Trustees of Caxton took the decision not to appoint a beneficiary as a Trustee due to the possible conflict of interest.

AW said that parity with MFT and ET should be upheld but that the ultimate decision was with them.

RE said that the charities should be made more consistent with each other.

RJ said that the longer term intention would be to merge all the charities together to form a Super Charity.

MH added that the charity and the beneficiaries should be on a par in connection with policies and that is what they are doing.

6. Publicity

AW suggested using existing mechanisms and contacts as there had already been one media blast.

MH asked whether we should advertise.

AW asked MH if he was comfortable not advertising, and asked him how effective he thought it would be to advertise.

RE said that the BBC showed a lot of interest.

AW said that the reporting was not balanced and that the campaigners were unhappy.

Ben Cole advised not to go for advertising.

AW suggested that if interest in the charity had not significantly increased by Christmas, advertising should then be considered but, in the first instance, given the limited amount of money available, it could be better spent elsewhere.

MH suggested a Caxton press release.

RJ thought this would be a better idea and more cost-effective and could possibly be considered to coincide with the October launch of the charity.

7. Staffing

RE advised the meeting that all members of staff had recently undertaken the HAY Job Evaluation process.

8. Visit to Alliance House

AW expressed an interest in visiting Alliance House. MH suggested an invitation to the DH to visit in September once the move to the 5th floor was completed. On that occasion, RR would give a brief overview of the work of the different organisations.

MH then went on to talk about the problems being faced in regards to the move from the 1st floor to the 5th floor. He told the meeting that he had tried to get a new lease for the 5th floor (which currently has 18 months to run under the current arrangement with Teletec). MH felt that this new lease would save money but the building management might not take an assignment of the 1st floor. So bearing in mind the 'value for money' intent favoured by the DH the surveyor came to the conclusion that trying to let the first floor at current market rent makes it favourable and the two transactions should be separate from each other.

RE said that we really needed to move from the 1st floor as soon as possible.

AW summarised that other than IT installation, other implications would be leasing the 5th floor and still having the lease on the 1st floor (c£43,000) with the rent still needing to be paid, but that this money could be funded through the MFT, ET, SF and MFET.

The surveyor felt that Alliance House may bear an assignment, which was better value for money than the original proposal to buy-out. The present value of the amount of rent outstanding was less than £125,000 which was not considered to be a major stumbling block. The DH was going to fund the proposal. MFT has to demonstrate that the charity's mission is value for money. The lease on the 1st floor expires in 2½ years.

MH said it was a case of cost over value and he would like the funds for the 5th floor to come through.

AW agreed that Caxton should move up to 5th floor as soon as possible.

RE said there should be separate documents for 1st and 5th floors. For the 5th floor buy-out the sum is c£125,000 but would need to find out if AH would come down on price. We could use the reserves of other charities to buy the lease out.

9. Trust Deed

AW said that MH would need to concentrate on the benefits when writing the Business Case for both floors. It was suggested there be an update meeting in September.

10. Actions arising:

- (i) MH to devise two business cases separating the 1st and 5th floors if possible.
- (ii) MH would try and negotiate with AH on the disposal options for the 1st floor and negotiate a reduced £125k estimate.
- (iii) RR to inform AW when the website goes live.
- (iv) Visit by DH to Alliance House to be arranged for October.