

Witness Name: Glenn Wilkinson

Statement No.: WITN2050001

Exhibits: WITN2050002 – WITN2050114

Dated: 14 August 2020

**INFECTED BLOOD INQUIRY**

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**EXHIBIT WITN2050101**

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**Please Note: The following report is CBC's take on the Caxton Foundation Partnership meeting and has not been agreed with any other person and/or group that attended, therefore this report does not represent an absolute account of the discussion (including context) however, it is a genuine attempt by CBC to reflect the discussion which took place in the meeting on the day.**

Caxton Foundation Partnership Group Meeting, 2 pm Tuesday 11<sup>th</sup> June 2013  
at the National Council for Voluntary Organisations (NCVO), Society Building,  
8 All Saints Street, London, N1 9RL

In attendance were:-

Jan Barlow – CEO of Alliance House  
Ann Lloyd – Chair of Caxton Foundation  
Charles Lister – Chair of NWC (Caxton Foundation)  
Chris James – CEO of Haemophilia Society  
Glenn Wilkinson – Contaminated Blood Campaign  
GRO-A – Contaminated Blood Campaign  
GRO-A – Co Chair Tainted Blood  
GRO-A – Manor House Group/Deputy Chair Tainted Blood  
GRO-A – Manor House Group  
GRO-A – Chair Manor House Group/Co Chair Tainted Blood  
GRO-A's wife

Charles Gore was invited but was unable to attend. Ann Lloyd said that she would be meeting him in a couple of weeks.

The meeting started with introductions. Interestingly, Charles Lister stated that from 1999 – 2003 he worked in the role that Rowena Jecock currently holds in the blood policy unit.

Ann Lloyd stated that she wanted a pro-active Partnership Group to help develop policies and strategies for the future. AL also stated that she didn't feel that Caxton was working effectively yet, but there was a real need to have a much greater dialogue with the partners such as the campaign groups and the rest of the Caxton beneficiaries. AL also wants to reduce the bureaucracy to the absolute minimum needed by the Caxton auditors and the DoH auditors to enable Caxton to get the money.

GRO-A asked if Caxton could put a business case forward to the DoH for extra funding in the same way that the MFT do. AL stated that they have to make a business case every year. AL said that Caxton have to justify the resources they have been given and secondly have a business case. AL also said that until 6 weeks ago, Caxton didn't have a strategy and "without a strategy you can't have a business case coming off the back of it." AL confirmed that Caxton now have a strategy they want to test with the community more generally as they take it forward.

AL said there could be 1600 people and 400 families that could possibly apply to Caxton for grants and so far they have had 600 applications. Glenn Wilkinson asked if the 400 quoted were part of the 1600 or if they were looking at a potential of 2000 in total. AL confirmed it was a potential of 2000 in total although she confirmed that it was extremely difficult to get any concrete evidence on the total numbers.

AL stated that Caxton were very concerned about the growing number of people who were being affected by the changes to the welfare system (as discussed at the recent APPG meeting) and was very concerned that at least half the resource Caxton have been able to allocate so far has gone on debt relief; these are the sort of issues Caxton are presenting in their business case to the DoH. GW asked when the business case was going forward. AL said that the DoH never consider a business case before November because in turn the DoH don't know until the January/February what their total allocation is, so each Government department from November onwards starts to look at the sorts of claims/requirements that are coming forward. AL said that Caxton has a constant dialogue with DoH officials about what's coming through Caxton's Welfare Committee and about what their aims and aspirations are, so that whatever Caxton put forward to them, it does not come as a shock to the DoH. **GRO-A** asked if the DoH realise how under-funded Caxton are to deal with the number of people coming forward. AL responded by saying that she thinks that it is the MFT that have that particular problem, but that is not the problem of Caxton at the moment, it might well be in the future, but MFT is in a very different position from Caxton.

**GRO-A** asked if the 'Carers' were written into the deed. Both AL and Charles Lister agreed that they were.

**GRO-A** asked where the carers fit in. CL said that Caxton look at applications for grants and support on a 'case by case' basis, but said that they haven't had that many requests from carers. **GRO-A** said that she is aware of carer's applying at the same time as their husbands however Caxton are saying to them that applications are dealt with on a 'case by case' basis and as Caxton have limited funds. Caxton have to deal with widows first because they have to live on a very low income because their husbands have deceased. CL said that they were not (certainly at present) giving priority to one group over the other and AL agreed with this.

**GRO-A** stated that from what AL said, "funding is not an issue at the moment" (and both AL & CL agreed that funding wasn't an issue) **GRO-A** followed up on this by commenting that the issue is identifying and getting hold of everyone who is eligible and making sure that they are aware of Caxton. AL confirmed beneficiaries need to also understand what they can claim, and AL admitted that this was one of Caxton's problems. **GRO-A** said that Caxton needs to get rid of paying people in 'Argos' vouchers. AL said that Caxton have done that. AL said that she had took that up with the Minister because she felt that some people might wish to be paid in that way, but that AL felt very strongly that people deserved to be treated with respect and honourably so that's now gone. "The choice is there."

**GRO-A** asked if the application looked at by the Trustees goes against the income of the household and is therefore means tested? CL said that Caxton ask people when submitting a grant application, to give information on their income and expenditure. (This subject wasn't concluded, as AL wanted to agree the aims and objectives of the group).

AL stated that she wanted 'us' to help Caxton to become a 'more effective organisation', including help on 'strategies and policy'. Glenn Wilkinson stated that "we have been trying to do just that, for a long time, and for 6 months now we've been trying to get a meeting like this together." **GRO-A** asked if Caxton envisaged that it is going to be more stakeholders (i.e. campaign groups etc) bringing information to them (as we are today) as apposed to beneficiaries coming along to air their views (as happens with the MFT). AL answered by saying that this is one of the things they wanted to pose to us. AL said "in terms of membership, there are you in the room and the Hep C Trust, but we would like to get a more effective feedback loop with the rest of our beneficiaries so for anybody who is interested would it be appropriate to invite them? Do we have this group or do we have separate feedback mechanisms for them?" **GRO-A** said that if this group is to try and help the running of the Trust itself, with suggestions and we can all agree, **GRO-A** felt it would be far better if "Caxton could maybe talk to somebody who would represent the widows, someone who would represent the carers, you could also then have someone who could represent whole blood, haemophilia and someone who is co-infected, so it would be relatively a small group but you could gain a lot more to go on with from two groups in that respect, because you would get the feelings of one group but you would be having the help from another group that's trying to help you to move forward as well." Jan Barlow asked if **GRO-A** was suggesting two groups. **GRO-A** replied, "another group besides this." AL said that there were beneficiaries who provide advice to NICE on Hep C and that; we need to draw them in as well. **GRO-A** said "that is the problem we have because we were promised at one time by Anne Milton that they were taking the whole bloods away from the Haemophilia community because we are different in a big context, the way that we need care, we need a lot more care than someone from whole blood that has been infected from whole blood because of the problems we've been associated for many years plus the other virus we've been exposed to which yet we still can't prove that we have, so therefore you wouldn't appreciate from another group mixture that they would put forward the greater need for our community. I'm not saying that we take preference but I understand that we can prove a need for greater need."

**GRO-A** said the alternative approach is that 'we as stakeholders' try and contact people that are within those contexts to make sure we get their feedback but at some point, the beneficiaries themselves would appreciate a meeting where they can air their views.

**GRO-A** asked if there could be a wider group like the MFT Partnership Group where anybody can go along. AL responded with "well, that would be the forum." Chris James asked if everybody is invited to the MFT Partnership Group and **GRO-A** said that it is open to all beneficiaries and anybody can attend.



[GRO-A] also said that you start to see similar faces who have an interest in bringing about change but you tend to revisit the same issues again and again without any apparent change and people tend to get put off by that and its hard to maintain membership.

Glenn Wilkinson said he thought there was the danger that the whole bloods would feel marginalised if there were separate groups, and that's one thing GW could definitely see coming from the whole blood people, "we need to involve them in discussion." GW said that this issue needed to be put to the community as a whole to see what they think. Jan Barlow asked if GW thought it would be more inclusive to have one group where anyone who was a Caxton beneficiary could attend. GW responded by saying that if there were separate groups there is the very real danger that the whole bloods would feel marginalised as if people with a bleeding disorder.... Both [GRO-A] and [GRO-A] said, "no we're not talking about separate groups." GW said that the way the discussion was going it sounded like we were having two separate groups. JB also appeared to think that's what was being asked for, was two separate groups.

It was finally agreed that this group become extended to include representatives of carers, widows, haemophiliacs and whole bloods. [GRO-A] asked if this would be at the same time or different meetings. AL said "no, we will have the meetings at the same time." Chris James said that it is difficult to get groups to represent everyone. AL said that we could have a forum for more general views. CJ said that from the forum you may get representatives as individuals as apposed to being members of a group. GW asked if the forum would be one physical meeting somewhere in the country once a year. AL said that once a year we will have a forum open to everyone. GW clarified that this would be a physical meeting, as apposed to an internet forum. AL confirmed that it would be a physical meeting, and then there is the Partnership Group with those important additions.

GW asked about the frequency of the meetings. AL said that it will be one forum meeting involving everyone once a year (but it wasn't clear what was being suggested for the Partnership Group meetings). [GRO-A] asked if it would be similar to the MFT Partnership Group meetings. [GRO-A] asked if the frequency could be dependent upon how the Trust was running, and if it wasn't running as it should be, could we increase the frequency. AL answered "I would like to take that under communication if you don't mind, because you can't just...." [GRO-A] clarified with AL that it was twice a year for the Partnership Group and once a year for the Forum.

AL said that she would like to aim the next Partnership Group meeting for November but "we've got to ensure that the communication between those times is effective."

[GRO-A] asked when they expected to get their business case into the DoH. AL said they aim to do this by the beginning of December.

Jan Barlow said that the biggest issue on the Caxton side isn't the money in the way that it is with the Macfarlane, "our biggest issue as Ann said is how do we go about trying to track down any other potential beneficiaries out there, so they don't need input about getting more money as that isn't Caxton's biggest challenge at the moment, it might be in the future if the potential 2000 come forward, then the chances are we would need more money, but at the moment, more money isn't the challenge. Our biggest challenge is making sure people are not slipping through the net."

**GRO-A** asked if the DoH could help in identifying these potential beneficiaries. JB said that she has been talking to the department regarding this. Caxton feel they have to try again to raise awareness and find other ways of finding potential claimants via the Health Service, GPs, newspapers, practice nurses etc. JB said it's probably easier to define those with haemophilia who have Hep C. DT said that Charles Gore and the Hep C Trust should be taken on board, and Ann Lloyd said that's why she was meeting with Charles Gore. **GRO-A** asked what steps Caxton were taking to identify those Skipton stage 1's/stage 2's who have maybe moved and Caxton were not able to locate - how many were there from that group. AL responded by saying one of the problems is that Caxton can't access Skipton's records. JB said, they can have access anonymously in terms of adding up numbers, but they cannot through Caxton, access all the info about those that have received stage 1. **GRO-A** asked if people could be traced through their NI number. JB said that Caxton had looked at the NI route but were told they couldn't do that because of data protection rules. **GRO-A** asked if the General Medical Council could help. AL said, no. JB said that there are five entities that operate out of Alliance House and if they were in separate locations around the Country it would be absolutely clear that they couldn't share information between those organisations but even though the five organisations are together they have to be treated as separate organisations regarding information sharing. Chris James asked when the Caxton Foundation was first set up, if the Skipton Fund wrote to all of its beneficiaries. AL said yes, and JB said that now, every time somebody receives a Skipton payment they are told about Caxton. Charles Lister said that the difficulty was those that had already received Skipton stage 1 and there hadn't been any contact for a number of years. Glenn Wilkinson said that he didn't think the Skipton stage 1's had been contacted as Nick Fish had told him that there were confidentiality issues relating to contacting them. **GRO-A** said there are also issues contacting stage 2's since the amount's been raised (after the review). CL also said that the problem was with the addresses for stage 1's as they can be old and there may not be the same people living there, so there are 'breach of confidentiality issues' contacting people at their old address. CJ said that the Haemophilia Society are very happy to do an article in the HQ magazine if it is needed. CL said that another 'hard to reach group' were the widows of partners who have had whole blood transfusion. CJ said it could be the same for haemophilia widows as well, as not all were members of the Haemophilia Society and won't be in contact with a Haemophilia centre. GW said that Caxton seem to be short on numbers by a considerable margin and asked if there was any danger that not knowing the full numbers of people within the community it could stop people getting the help they need now.

GW said, he asks the question specifically as he knew Caxton were looking at the issue of possibly paying some sort of ongoing support to stage 1's who don't get any sort of non discretionary payment and GW was told that one of the issues might be that Caxton are not totally sure of the final numbers as yet. [GRO-A] said "you wouldn't delay support would you until you identify the whole community?" AL said "no, no, we couldn't possibly do that, it would be so unfair." GW said he was glad to hear it. JB said that the department was aware that because of the gap in numbers (the potential numbers and the numbers Caxton have at the moment) they had said that they would be open to Caxton going back to talk about increasing funding, if suddenly through the exercise of advertising it did result in more people coming forward. [GRO-A] said that there was no issue with money coming forward in that respect – he did know that. [GRO-A] asked what the maximum projections were "as you hear silly figures of a hundred thousand". AL seemed very surprised to hear this. JB said that the anonymous data that was taken from the Skipton Fund made various assumptions and projections; it was about 1500 primary beneficiaries and about 400 or 500 dependents. GW said, "about 2000 then." AL and JB confirmed about 2000 max. [GRO-A] asked what Caxton classed as a dependent (apart from the wife). JB and CL confirmed children in full time education up to the age of 21. [GRO-A] asked about children over 21 who are unemployed. JB said that they weren't classed as dependents. This was confirmed by CL. [GRO-A] asked if the information was on the website. CL said it wasn't listed explicitly.

GW asked if 'we' get to see a copy of the business strategy or is it strictly between Caxton and the DoH. JB said "depends what it looks like to be honest, what the assumptions in it are and the discussions with the department really". AL said that it wasn't a secret as far as she was concerned. GW asked if 'we' could possibly see a copy. AL said "certainly when we've gathered your views." DT said with regards to the final decision on that aspect, we can't change anything in that, we appreciate that. AL said it has to be utterly realistic and that in her experience you don't get anywhere by playing the band on these things "you've got to have absolute realism and that's what Caxton will do."

AL said that Glenn mentioned the legal status of, and membership of the Caxton board, and said "this was all done before they got there." JB followed by saying that there had been some confusion about the 'status of the board of Caxton'. She explained that Caxton was set up as a Charity and for the first x number of months (best part of a year) after it started operating was a simple charity, and as JB understood there were issues raised about individual trustee liability and as a result of that, the decision was taken to also create a Limited Company before Caxton 'was well'. JB explained that a lot of charities have dual registration both with the Charity Commission and Companies House, JB initially thought the same thing applied to Caxton, but when JB looked into it further, it was only the Trustee Body that had been registered as a Company, so technically, although "we internally refer to the 'board' as Trustees, they're actually company directors and it is the corporate body called 'Caxton Trustee Limited' (which is the bit that is registered with Companies House) which is a sole corporate trustee. So technically, we don't

have trustees, we have directors, but it's only the trustee board, not the whole organisation that is registered with Companies House. So, we will probably just through 'force of habit' because everyone well, a lot of people were appointed as Trustees, continue to refer to people as Trustees colloquially, but actually the people who are on the board are technically 'Board of Directors' but that incorporated body called 'Caxton Trustee' has to operate to the Charities' trust deed and has exactly the same responsibilities as if that had never happened and they are still trustees. So this is actually a very boring technical legalistic point that a lot of people won't even be remotely interested in, but it was raised and we thought it was just useful to try and clarify that." AL said "it was all because of personal liability we understand, but the Trustee Board (from my point of view) operates as Trustees but against a good governance framework. We all remain unpaid, we all remain as we would have been had this not come about, but it was about Trustees at the time who were very concerned about their financial liability as at the time they were going to move to new premises (it was before AL & JB's time) which hasn't happened, and we're quite content to stay where we are because it would cost to move, so that's what happened." JP asked if it created a separation between the beneficiaries and the trust, for instance in accountability. JB said she didn't think it would make the slightest bit of difference, as in all the charities JB has worked with before, they have had dual incorporation so the Trustee is equal to the company directors and it makes not a 'blind bit of difference'. AL said "and the trustees as appointed have been appointed as Charity Trustees and are responsible." JB said "although legally they're not trustees, legally they're company directors who are registered with Companies House". AL said "it's extremely boring". JB said that if we looked on the Charities Commission website, the Trustee of the Caxton Foundation is 'Caxton Trustee Limited'. Again AL said "it's very very boring." [GRO-A] asked what the liability was they were protected from. JB said Caxton could not overspend as they don't hold reserves, but gave an example of signing a contract for a lease for however many thousands of pounds, if it was signed as an individual and something were to go wrong, potentially that liability could come back on 'you as an individual'. GW addressed AL and said "so technically you are a company director, not a trustee, but you're calling yourself a trustee?" and AL replied "yes". JB said "yes, just colloquially as everyone started as trustees, it's difficult to get out of the habit, of people calling themselves trustees." GW asked if the information on the Charities Commission website was going to change and both AL and JB said that this is now changed. JB said that "it was a complete 'oversight' that hadn't been done, but obviously it was from May last year, I wasn't here at the time but as soon we were aware that needed updating we did it, and if you go on the Charities Commission website now it says Caxton Trustee Limited, not the individual people."

AL said that additionally in terms of membership, they were working with the Hepatitis C Trust to establish a new Trustee who has experience of living with HCV, its one of the things they will be talking to them about in 2 weeks. [GRO-A] said that he had an issue with that, and said that "we want a foot in the camp as well because they wouldn't best serve our interest, someone who has been infected from whole blood." JP said that it depended on who they were talking

about, is essentially a mono infected hep c whole blood person with that sort of prospective or whether it was somebody who would also have haemophilia on top of that, that would understand the multiple contaminant angle as well and JP thought out of fairness you might expect to have equality there so there is equal representation. [GRO-A] agreed. [GRO-A] also said that they found that because the Hep C trust were awarded the money for counselling, many people didn't come forward, because they felt the Hep C trust didn't represent them. [GRO-A] thought the Haemophilia Society should have been awarded monies for counselling because they could best serve the needs of those with a bleeding disorder and have a better knowledge of the community including issues of disability and bereavement. [GRO-A] requested that the new trustee would be somebody with the knowledge of haemophilia if possible. [GRO-A] also said "it was fair to say that in the past we've seen the Hep C trust make their own way in terms of how they meet and make representations and that hasn't always been to the benefit of the wider community, and certainly haemophiliacs." AL said that they will take it on board. [GRO-A] said that he had challenged the Minister on that issue and she had to admit and so did the expert group there was no consideration taken for the haemophilia community on the way the virus affects our community. "All the research was done on the general public including alcoholics, drug addicts and people like that. Therefore the Minister accepts now that there is a difference between us that's why we are still pushing for a separation." [GRO-A] said "we raised that concern with the Minister when it was first announced that we didn't think people would go to the Hep C Trust and we came out of that meeting agreeing that we put a concerted effort in to encourage people to do that, which we did, and we're still not seeing people, people are put off the fact that they are not 'haemophilia' orientated and they do not understand the community." [GRO-A] said that Rowena (Jecock) accepts that fact as well, "it's a shame, but that's what's happening." AL said that this was really helpful and that they would be taking all that on board and liaise with [GRO-A]. AL said "Thank you on that, but I think its really important that we do have somebody who complements and completes our 'board' who is coming with that sort of skill-set and knowledge, its important."

GW asked if there were any plans to have a 'user trustee' or user trustees on the board of Caxton to create a 'read across' between the MFT and Caxton "because we feel it is very much needed." Charles Lister said when they are looking for someone who is living with HCV to be on the board (that person may or may not be a 'user') the difficulty for any 'user' would be the conflict of interest issue and if a 'user' did apply to be a Trustee, then part of the consideration going through the interview process would need to be how that individual would deal with any potential 'conflicts of interest' if they were a beneficiary of the charity. GW said that the MFT manage it and GW understood that the MFT had 3 user trustees. CJ said, "no, they have 3 trustees appointed by the Society as part of the Government's process, but "we don't necessarily choose 3 'users' to be on it." The Society makes the decision based on people coming forward and makes the appointment, and CJ thought that even with that there are probably issues in terms of appropriateness etc and it is something that test's the Society's board when they are making those decisions as well so you have to be very careful about

how you do it, and that one of the issues about choosing a board is that what you want is the skills and experience to actually govern the organisation. CJ said he gets slightly worried when he hears the word 'representation' when it comes to a board because actually "the board are there to govern the organisation." CJ said that he knows where GW is coming from and the Society do appoint user trustees to MFT and have done for a number of years, but it doesn't necessarily have to be a 'user'. CJ also said the Society do have one person who is a beneficiary of the MFT, but the other two don't have to be. GW said that at the moment "we don't have any 'user trustees' on the board of Caxton." JB did say that she was aware in the past of a 'user trustee' of MFT resigning because they found issues about conflicts of interest so challenging they couldn't reconcile their responsibilities to the organisation (if you like) with their own issues, and JB thought there was more than 1 person who had stood down because it was a challenge for them personally. JB said "that the way the Caxton board was going, is to recruit someone who has experience of 'living' with HCV and kind of take it from there, and its still early days really, with the board already quite large, so we have to take it from there." GW asked if the person they intend taking on will have experience of living themselves with Hepatitis C. Both JB and AL confirmed that they would. CL also said that this is what the board lacks at the moment. [GRO-A] commented that it would a sensible thing to do in relation to the people Caxton are looking after, because at least they'll know that there is somebody there that has some common knowledge. AL said that "Caxton have Howard (Thomas) who comes at it from a medical point of view so understands the research and developments and that's important, and he adds real value to the board, and Caxton felt, that this was an absence."

AL said regarding the 'Mission, Vision and Values', that they have had their first meeting as a board about Caxton's strategy, our vision, and they have prepared a very, very early draft. One of the things the board was thinking about is that they wanted "everyone who had been affected by Hep C derived from the NHS to be able to live a positive, fulfilling and independent life. And to identify those that would benefit from 'our assistance and work with them to improve the quality of their lives, and those are the core values and to make sure that Caxton has much better communication, effective intervention and help, and ensuring that Caxton are well and appropriately resourced, and these are the principles on which our business case will be developed over the next 18 months." AL said that she would like to have our comments on this. [GRO-A] said that the applications are taking far too long and that the trustees should be meeting on a more regular basis. [GRO-A] said that the problem appeared to be with the NWC, and that they're only sitting every 4 – 6 weeks. GW confirmed that originally it was 4 – 6 weeks, but this changed to 6 – 8 weeks and that when CBC met with Martin Harvey last July, we expressed our concern at the increase and was told that this would only be a temporary thing, and that he would take it back to the board, but nothing has changed. GW said you can be looking upto 3 months for a single application and if further information or evidence is needed, this time period can be doubled. [GRO-A] asked if Caxton had clearer guidelines and procedures that people have got to go through so they can do that and the 'goalposts' aren't changed (because I'm hearing stories of people doing things and then

changing things that they need, to qualify) [GRO-A] also asked if some levels of support could be approved at office level, to speed up the process. JP also said what was coming through 'loud and clear' (and I am sure you will want to address this) is the attitude of the staff, it maybe frustrations and so on, but we really do need to see more empathy and passion coming through. AL agreed and said "absolutely". GW said that it wasn't just the staff as GW had made several attempts to contact Ann Lloyd and Jan Barlow, but doesn't receive an email or telephone call, and it can go on month after month, and that is frustrating. AL apologised if that is how GW is finding it. [GRO-A] [GRO-A] made the point as an MFT registrant for many years, whenever he has applied for discretionary grants, [GRO-A] never seemed to have the delays and the problems that the Caxton registrants have had this last year, and the feedback CBC have had, has been absolutely terrible, therefore why haven't Caxton 'read across' some of the policies and procedures that the MFT use because surely that is what the Government intended for a 'read across' in many cases of the MFT. [GRO-A] said it seems the processes are very long-winded and taking a very long time and the stress that it is causing people is terrible. GW said the 2 major issues are, communication is a massive issue (or the lack of it) and these delays in the application process.

AL asked Charles Lister to explain what the NWC are trying to do. CL explained that the Welfare Committee meets every 6 weeks but they do have a set of guidelines for the office about grants that can be approved by the office without reference to trustees. They have tried to make it as comprehensive a list of guidelines as possible and it is reviewed regularly at Welfare committee meetings to make sure its current and doing what they want to do, and quite often the staff suggest things that could be added, so that should improve 'turnaround time' in a lot of cases. The other thing they do is they deal with a lot of cases by email in between the physical meetings so if cases are urgent, they come to us via email and the Trustees will normally respond to those within a 'day or two'. CL said as far as meeting every 6 weeks is concerned (it is normally every 6 weeks rather than every 8 weeks), bearing in mind that the same team that is putting the paperwork through to the NWC is also putting the paperwork through to the MFT's committee. The 6 week interval seemed to be a reasonable sort of 'compromise' on consideration by the Trustees of those fewer applications now that have to come to us and the staff's ability to service our trustee committee as well as the Macfarlane Trust one. [GRO-A] asked if the money is shared between the Macfarlane Trust and Caxton on the staffing issue. [GRO-A] asked if they are they being paid for Caxton work. Jan Barlow explained there are 11 staff (not all full time) who work for all 5 organisations; across Caxton and Macfarlane there are 5 staff in addition to JB who do everything for both, and there was an agreement with the DoH saying, of these different staff, x proportion of their time will be used on Caxton, Macfarlane, Skipton, MFET, Eileen, so when you kind of aggregate all the percentages, you're left with 5 staff doing everything for Caxton, Macfarlane. JB said they can't breakdown exactly how much time is spent on each because they don't do a 'time and motion' study. JB said that the 5 staff are doing Finance, IT, all the backroom functions and on the Macfarlane side they are processing all the discretionary payments, they are doing 2 rounds of grant committee's every 6 weeks, and

its kind of not an excuse because there are things within what they are already doing, that they need to be doing better. JB said she spends a lot of her time working on that, and hopefully by the end of the year, beneficiaries will see some significant improvements. JB commented that [GRO-A] had raised this issue at the recent APPG meeting and asked if it was about 'bad practice and bad equipment' or is it about 'lack of resources'. JB said that it was about both because the department's been very clear because they have 'capped' the number of staff they are allowed to have. GW commented that it seemed quite odd that they are not restricting the amount of money they can have to run Caxton, but they are restricting the amount of staff, so one way or another the department are stopping (with the delays in applications) people getting the help that they need. AL said that Caxton need to make the most effective and efficient use of the 'cap' that they have to work with. AL said that JB has been doing a review of the skills, competence, capabilities needed to improve our situation, because it is too slow, too bureaucratic. JB also said that as the staff have been at Alliance House for a long time only dealing with MFT issues, there is a 'mindset' change, which needs to go. JB also said that she is aware that some of the people that answer the phone aren't as polite as they might be and that JB is addressing the issue, but can't say too much about that at the moment.

JB also mentioned that [GRO-A] had raised the issue of providing comprehensive benefits advice during the recent APPG meeting. JB said, "if we were to do that in a comprehensive way by employing a full time member of staff, the fact is, the department are not going to give it to us so we're kind of stuck in this 'how much are they prepared to spend on the kind of support that people want, so going forward that is part of Caxton business case, and if the department don't want to give 'that to us', we can't go elsewhere for money because of the way Caxton has been set up, so we're kind of stuck having to effectively cover the basics." [GRO-A] made the point that using the services of Neil Bateman comes at a cost to the Trust each time someone is referred. [GRO-A] asked if [GRO-A] had an idea of how much that was costing annually or per person. [GRO-A] made the point that this must be costing a lot and would it not be cheaper to employ somebody full time. JB said that its not costing as much as it would having somebody in-house, and also the expertise that Neil has, you would have to pay an awful lot of money to have that in-house. JB said it's a challenge, but if someone said "here's a blank chequebook what would you do? we would probably have a benefits adviser, an in-house debt adviser, we might have a surveyor because one of our issues, almost second to the debt issues are property issues, so to give people that support – I could go on with the number of additional things that we could do, but we can't do them without the money to do them, because the absolute 'bread and butter' (certainly on the Caxton side) is the grants – because that is the way we support people, and on Macfarlane its grants and discretionary 'top ups' so were kind of stuck really at the moment." [GRO-A] said he was disappointed that Caxton haven't got the means to be able to provide these sorts of services but equally the department haven't provided the Haemophila Society with the means to provide the sorts of things they used to be able to do. JB said she shares our frustrations (on a daily basis) in terms of those things that Caxton could easily provide if they had the resources to do it, but at the moment they don't so



can't do much with our concerns, apart from raise them with the department in terms of funding. GW said that as individuals when we lobby our MP's that is something that we can be asking for and as campaign groups when we meet with DoH officials this is something we can raise as a group. GRO-A said that "there isn't enough staff and Caxton haven't got the finances to provide enough staff. GW – they've put a 'cap' on you, stopping you. CJ said "the Society would do what it can to work with Caxton, MFT and the benefits support (Nigel Pegram) in order to provide that and we have got his expertise that we can use, but he is quite limited with his work with the society." GRO-A said that Neil Bateman has a legal background which gives him an element of expertise, but he doesn't really have the haemophilia background and to an extent what GRO-A has heard, Neil Bateman has to rely on haemophiliacs to help him and his interpreting of the rules and the legislation such as GRO-A mentioned in the recent APPG, there does seem to be generic advice and maybe if everyone put their 'heads together'? GRO-A said that he has managed to 'glean' the legislation and the specific rules from the capability questionnaire's and so on, if you can add into that the expertise of haemophiliacs and what they found relevant, there should be a way of producing something which isn't going to cost very much and which is there for everybody to read. JB said she thinks that Neil Bateman's greatest strength is his legal background and he has had an enormous amount of success challenging decisions so for most people that have had dealings with him, there is a lot of success in what he does. GRO-A said he agrees in challenging decisions but thinks there should be more success in successful decisions in the first place preventing people having to go to tribunals to challenge the decision. Jan Barlow said that that goes back to the discussion that was had in the recent APPG meeting with the DWP. JB said that Neil and herself were going to see James Bolton (DWP) in a couple of weeks to talk about and follow up those themes brought up in the APPG about whether there are any kind of things we could do across the community to spare people from constant reassessments, when people made the point that they were 'retired' from work on the grounds of ill health and there's no chance that people are going to get better from this, so what's the point of these constant reassessments. JB and Neil are going to talk to James about things like that and hope that 'we might make some headway' but obviously some of it is down to individual local authorities, so lobbying at National level on a lot of things is not going to work anymore unfortunately.

GRO-A asked, as the carer of a haemophiliac what kind of things are they allowed to claim for? Holidays, or pamper days, or things like that that they can't possibly afford? GRO-A said that there was a problem, as a carer of a haemophiliac she can't say exactly when she would be able to take a holiday because as the carer of a haemophiliac the holiday might have to be cancelled and she also made the point that when applying for a holiday it wouldn't be possible to specify the date the holiday would take place. GRO-A asked if it would be better to give the carers of haemophiliacs a set amount of money at the beginning of the year for holidays, pamper days, or to go to the cinema, or whatever, "but we have to do it when we can, we cannot plan anything." GRO-A also said "as carer's of haemophiliacs we cannot tell you from one day to the next what we are going to be able to do" and said that it would

save Caxton a lot of bureaucracy if they made one payment to the carers and then the carers sent in the receipts "if and when they get them and any finances that are left they'd have to agree to return it." Charles Lister said that Caxton certainly funded respite breaks for carers and there would be nothing to stop them (and he was sure they had done) agreeing this for a carer – so it's agreed and then when the carer's need to claim the money they can claim it. [GRO-A] made the point again that she couldn't say exactly when the break would be taken and sometimes the break might have to be taken at short notice, so would need the money there and ready for when her husband is well enough to do these things. JB said "we can do that under the changes we made, people have a choice of whether they want vouchers or whether suppliers are paid direct if you [GRO-A] were to apply for a grant for a respite break and you'd decided when its possible for you to go 'I'm going to go to that place for this number of days costing this amount of money'. If you applied for it on that basis we could release the money to you and you'd have to send us the receipt when you'd actually been, so that wouldn't be a problem in that case." [GRO-A] asked what would happen if she couldn't go for 6 months, 9 months, 12 months. JB responded by saying "you'd still have that money." AL said "because the grant had been given – it's not time limited." [GRO-A] said that if she had told Caxton she wanted a week in Wales (for example) but wasn't able to manage a full week, would day break's be acceptable because she had already asked for a week. AL said "yes, as long as you've explained and provided receipts." AL said that the basic principle is "a break for carers." [GRO-A] then asked if carer's were assessed on their husband's income or on "our carer's allowance." CL said that he didn't think income would make any difference if you were a carer. AL said "I don't think it's an issue." [GRO-A] asked the question "then why are we asked to send in all our husband's benefit details." This question was not answered at that point.

[GRO-A] said that at the recent APPG meeting AL & JB said that they were asking for information they felt they shouldn't be asking for (on the application forms) and that when campaigners met with Anna Soubry last November, she did say that she was going to simplify the forms. [GRO-A] said that the previous Minister also said this 12 – 18 months before. GW said that Anna Soubry said she had seen the forms and that she was "less than impressed." (AL said "yes, that's right). GW then went on to say that Anna Soubry was meeting with Caxton to discuss it however, GW said that he is aware that people are still receiving the same forms, and they're exactly the same. GW asked if anything had changed. JB said that essentially there were two issues, one is that when Caxton was originally set up because they didn't know how many people were going to come forward, Caxton didn't know whether or not they would have to means test the support they gave, because the first charitable filter is 'illness and disability' so everyone's equally been infected even though the impact may be different on different people. The next filter is 'financial need' because when you are trying to assess how you spend charitable money then you may have to put some filters on it. At the beginning, because Caxton wasn't sure whether it was going to have to means test the grants and the support it gave, it asked for a similar level of financial information as the Macfarlane Trust does and what has happened over the course of the first 18 months, Caxton have seen that they are not yet

in a position where they are having to really means test support. JB gave the example of where the beneficiaries received the winter fuel payment which wasn't means tested, but on the Macfarlane side that's graded for levels of income, because of the financial constraints. JB said it was one of the first observations she made when she joined "if we're not means testing any of this stuff why are we asking for an annual census that asks for that information because we don't use it to assess things like winter fuel payments so we've already agreed that any annual census at this point in time will only ask for basic details because we need to keep your information on file so that we can inform you about what's going on and invite people to events, all that kind of stuff, but we don't need all that detailed information as part of an annual census. When it comes to grant support through the NWC on the whole we are also not making our decisions about whether we give people support on people's level of income however the biggest thing that has come out of getting the 'income and expenditure' information from the grant process is that what it has done (in probably the majority of cases) is its flagged up that people have a lot of underlying financial problems that asking for a grant is just a symptom of. For example, someone might ask for support with something very specific because they can't afford it and it reveals that they are paying so much back (say on credit card debt) they can barely keep their 'income and expenditure' ticking over from month to month. If we didn't ask for that income and expenditure information, we wouldn't get that information and what we've been able to do as a result of having that, is we've been able to get people debt advice; we've been able to get people's debt written off, we've been able to get referrals to benefits and get decisions challenged which we wouldn't have been able to do if we hadn't had that information; so at the moment we think it would be the right thing to do to continue to get that income and expenditure information from people when we are looking at grants, simply because our experience is that that throws up a whole load of other areas where we have been able to give people a lot more support which people themselves might not identify or maybe a little bit embarrassed to ask." JB also said "it's still quite intrusive, we appreciate that being asked to send all that paperwork must be very, very difficult for people." JB said that the general principal is that Caxton don't want to ask for information they don't use. JB then said "the census we'll move away from it; for the time being in relation to the grants because it gives us so many insights to other things enabling us to give support to people, then we will continue to use that for now." GRO-A said that as a carer why does she have to supply her husband's income when she only has her income from the Carers Allowance as she is an individual. JB said that the decision was that it should be about household income. GRO-A asked even though they were on state benefits its still about household income? JB said "yes". GRO-A said that there were lots of anomalies that creep into this as a partner might be on a good income, or have had to reduce their hours, but are still over the threshold that Caxton consider to be 'needy'. CL said that at the very beginning of Caxton they looked at how many beneficiaries might come forward and what the demand might be on the resources Caxton had and they took a fairly cautious approach to begin with and part of that was thinking that Caxton would focus support on those with the lowest incomes and that's were the £14,000 figure came in, because that's the Government's official poverty line. CL said that Caxton haven't

actually used that in their decision making for quite some time. [GRO-A] said that there was also an issue which was raised in the meeting with Anna Soubry last November that the poverty line used or applied is wrong because it doesn't relate to people with disabilities. AL said "But we're not applying it, I think we need to make that very clear on the website." [GRO-A] also asked that the things that have been addressed, are they being widely advertised to the beneficiaries because if they don't know its there then they are not going to apply and its acting like a filter. AL agreed and said that it was so important for Caxton to fully ensure that they do have effective contact with the beneficiary community. [GRO-A] said that not all beneficiaries are on the internet. AL said "I understand that, I don't just mean the website." [GRO-A] said that her husband is registered with the Caxton and has never ever had any information sent to him from the Caxton, never. [GRO-A] also said that her husband wouldn't know, or she wouldn't know what sort of things they could apply for, they wouldn't even know if funeral expenses are covered and if it is, would that just be for the Hep C victim or for the Hep C victim and his partner, because they can't get insurance and that its not just the victim, the partners can't get insurance so will the partner's funeral costs be covered, "we don't know because nobody tells us." [GRO-A] said that Caxton doesn't work on the same lines as the MFT, as an MFT widow has ongoing monies paid to her when her partner's deceased and as such all monies are made up to a certain amount but that doesn't happen with Caxton. When the recipient of Caxton passes on, the woman/partner/wife doesn't receive a penny, then that person is left and [GRO-A] said he had said to the government at one time widows are left "to queue up outside of a social security office and beg for monies through no fault of their own even though she'd married that person, yes she knew what she was taking on, but no she didn't expect what was to come." [GRO-A] said he told government that they had a moral duty to treat widows and partners of those who are deceased, at least by funeral costs and ongoing costs such as the Macfarlane Trust because although [GRO-A] know's that the Macfarlane Trust don't get 'sometimes as good as Caxton recipients and it's a 'mixed bag' therefore [GRO-A] would like Caxton to tell the Government this and [GRO-A] said that the two trust's need to be 'on par' with each other. [GRO-A] said that there were some issues, particularly with co-infection issues and so on where you may need to be able to respond to a disproportionate type of parity; you get issues in co-infection you don't get in mono infection, but equally there are some things where you should see a parity in the support framework for widows and dependents after the person has passed on. [GRO-A] said that these are the sort of things that should be addressed and we should be able to see some sort of relationship there. [GRO-A] said that it would provide a better working relationship for Caxton as well where everything is more straightforward. JB said that it is a 'huge challenge' as (she is) the one person in the room that works across both, as in the Macfarlane side the bulk of the money that the Macfarlane gets goes to regular payments and on Caxton side it only makes grant payments. JB also said that "the people who don't get the regular payments that Macfarlane get, on the Caxton side think that's unfair and on the Macfarlane side look across at Caxton and go "well you don't get means tested, you get across the board winter fuel payments." JB said that there are pro's and con's both ways and thinks that the biggest challenge is that the Macfarlane Trust has been running for 25 years and a lot of what it does and the ways in which

it supports people, are completely imbedded in the historical way of doing things which (JB was sure) MFT beneficiaries would (if Macfarlane wanted to create parity with Caxton by doing away with regular payments and all it was going to have was a grant system) there would be outcries from the MFT community about removing discretionary top up payments and so it's a real challenge simply because of the histories and the policies that have developed and the expectation put upon Caxton was that it would be a grant making trust. [GRO-A] said that Caxton's loyalties should lie with people that they serve. JB said that it comes back to the fact that if one was in Newcastle and one was in Exeter ... AL said "its got to be absolutely clear what support we are able to do and not via the internet solely, but make it very clear what the limits of our authority are at the moment and to glean from 'you' (not a shopping list, I don't want any shopping lists) what would be a positive benefit and you've raised the issue of widows/partners and the way they are managed and treated and that is already on our radar given the requests that we're having at the moment." [GRO-A] asked "if we claim for a funeral bond as our husband's can." AL replied "yes we've already granted those." [GRO-A] asked for clarification if this was for the carers as well as for the husbands. AL and CL both said "I don't see why not." [GRO-A] said that she had been told by Anne Milton by letter via her MP that the Skipton Fund money is solely for the Hepatitis C victim and not for partner's and family – it is solely for the Hepatitis C victim and [GRO-A] made the point that in effect the carer's and partners received nothing. [GRO-A] said that MFT works differently because it carries on for 12 months and potentially longer. [GRO-A] then said that if the husband/wife died and they were receiving carers allowance, that would finish after 4 weeks leaving the widow with nothing. [GRO-A] then said that this is why we campaign for widows because they would then have to go 'cap in hand'.

[GRO-A] suggested that Caxton make contact with Mark Simmons, a social worker at the hospital he attends and suggested this might help the communication Caxton are going to have with the DWP. [GRO-A] stressed that they 'drop him a line' as he would do an excellent job (regarding benefits and he has attended tribunals). JB said that she talks to Mark all the time.

GW asked if Caxton have any plans to 'lift people out poverty such as widows, stage 1's; people that you can see who are receiving very very little. GW said there is a lift up to £19,000 threshold for widows on the MFT. GW made the point that if there is no restriction regarding finance for Caxton then surely the DoH should be funding that. CL said that there was no restriction subject to Caxton putting in a business case, but it's having a business case accepted. CL said that one of the things Caxton were conscious of on the Welfare committee is that there are a number of people who come to them for 'one off' grants or a series of grants who are 'living hand to mouth pretty much' and sometimes it feels like just giving them a grant for a new fridge is insufficient. GW agreed. CL said there was a question about what Caxton can do there within the scope of how Caxton have been established and that is something they are going to be looking at as a board. CL said that Caxton will be wanting to look at a number of options. AL said that they will be looking at a number of case studies and have started discussing this. GW asked what Caxton class as the poverty threshold for beneficiaries. GW said that he

assumed it was £19,000 for MFT as they have topped the widows' income up to £19,000 for the MFT, therefore is it the same for Caxton. AL said that they haven't discussed the poverty levels for Caxton yet. JB said that it was important to say that whatever Caxton did, they would not be looking to recreate the kind of discretionary top up system that operates from Macfarlane and JB didn't think that Caxton would get the Department's support to do it even if Caxton were to suggest that, so what they would be looking at is how they can give those people (as CL said) who look as though for particular periods of time are living almost 'hand to mouth', how Caxton can support those through that period by giving additional support to make sure they are accessing all the benefits they can or by giving them money management advice (but it would not be anything like the Macfarlane discretionary system). GW said that it was a 'massive anomaly'. AL then said that is one of issues about how Caxton have been set up. JB then said "that's what we have to live with." GW said that that is what can be put forward as a business case to ask for Caxton beneficiaries to be lifted out of poverty. JB said, when Caxton was set up the Department made it very clear that it was to be a discretionary grant making trust so they would not support the use of the money in that way. AL said Caxton have got to look at the anomalies (not the anomalies between the organisations), but the cases that Caxton are getting through and how best those problems can be alleviated, that's what were doing. CL said that there needs to be a balance somewhere but what CL doesn't want to end up with is, in the same way that MFT doesn't have the flexibility that Caxton have, to give some of the types of grants that Caxton do CL wanted to keep that flexibility for us, so Caxton need to look at what's possible. [GRO-A] said that when MFT was set up over 25 years ago, it was doing essentially what Caxton are doing now. MFT were set up and providing grants and were seeing the same sorts of things, people were in debt and basically, a little ongoing support actually helped and got them out of problems, so this is where the very first regular payments came from and they have grown into what we see now. [GRO-A] made the point that regular payments helped to offset the need for repeat applications. [GRO-A] also made the point that some people apply for assistance from Caxton but there are also a lot of other people out there who won't approach Caxton because they don't want to be seen as begging or they find the process off-putting, so to reach those people, Caxton need to make the grant system either very easily accessible or find other ways such as the regular payment that Macfarlane Trust brought in and then that reached everybody and offset some of that inequality. [GRO-A] [GRO-A] said that at the moment, Caxton's application process is absolutely humiliating.

[GRO-A] asked if would be possible for Caxton to make a business case to the Department to say that the grant system is not sufficient for people and make a case for regular payments as [GRO-A] understood that is what happened with the MFT and how post Archer, the payments were made up. [GRO-A] asked if it would be possible in the business case Caxton are undertaking, to include a case for making for regular payments for people. GW added, 'as a lift out of poverty'. Chris James said that to do that the application evidence is needed for the business case. GW said that there is 'a mountain of evidence and if the effort is made, a case could be put forward'. AL said that

the issue is being seriously discussed. CL said that he thinks this is something that Caxton need to continue looking at as a 'board' but as AL said, it is seriously under discussion.

GRO-A said that there is no doubt, there are definitely people in stage 1 who are ill who will never, ever get to stage 2. GRO-A said that with some of the newer medications, they are helping the medical situation a little, but instead of 'curing' people as they keep bandying this term around, it's not really a cure because the people have lived with these diseases for so long it's creating a lot of protracted disability and illness instead. AL said that Caxton appreciate that. GW read the following from last year's Caxton accounts, which he found quite a worrying statement...

*"HCV can be cleared either through treatment or (very rarely in the chronic stage) naturally, with a success rate of treatment, for those not co-infected with HIV, in the range of 40% to 80% (depending on genotype); it is probable that many of those who have cleared the virus will not have needs that are suitable for charitable relief."*

GW made the point that this statement makes the assumption that once you've so called 'cleared' the virus 'go away, there's absolutely no problems we won't need to support you', which isn't true. GRO-A made the point that you can move into stage 2, years later having 'cleared' the virus. GW said that the compounded effects of the virus and treatment and various things has been horrific. GRO-A said that he had asked this at the meeting in November last year, he asked if the experts looked at the people who 'cleared' the virus on treatment, because they have never taken into consideration, the long-term effects of having these poisons such as interferon put into them. GW made the point that Professor Howard Thomas is on "you tube" saying a similar thing and that worried GW because as Professor Howard Thomas is a Trustee on the Caxton Foundation, if he is of that mindset of people who 'clear' the virus, then what hope have we got. GW also thought that some of the information that Professor Howard Thomas has given Caxton is 'flawed'. GW said that he has tried on many, many occasions to speak with HT and he just blanks every attempt GW makes to contact him. GRO-A said that there was a discrepancy between the way that Skipton are looking at evidence in the way that it's potential being applied to Caxton. Skipton took on a review themselves and accepted evidence which shows people who have been infected with Hepatitis C if they're in the haemophilia population, co infected they are considered to be in the advanced stage of the disease or in cirrhosis after 16 years and for a single infection, 32 years. GRO-A said all sorts of evidence was used and there is a paper that had been produced from that, and that is what is being accepted; Skipton are applying it for estate claims where people haven't got evidence but they do know that they were given NHS products so Skipton can say 'fairly categorically' this person will have had 'advanced disease' which justifies making the stage 1/stage 2 payments. GRO-A then went on to say that that same realisation hasn't filtered down to 'ourselves' where most haemophiliacs have been living with the infection (even before they were treated and 'cleared' it, if they were able to) for maybe 30/40 years, so they're well over that 16 year period. And in fact probably a lot of the whole bloods that you come across are well over that 32 year period

as well, so to say they have gone through treatment and 'cleared' it and everything is rosy now, isn't supported by the evidence that is out there. AL said that it was very helpful actually.

GW wanted to come back to the point **GRO-A** had raised earlier about the office guidelines and about knowing what people can claim for. GW said he knew for a fact that Caxton have office guidelines (AL confirmed this) together with amounts put against each of them so is very clear what can be claimed for, but the problem is that the community don't have a clue what they can claim for including amounts. GW said that when CBC met with Martin Harvey last July, Martin Harvey said that he would take our request back to the trustees and ask if the office guidelines could be posted on the Caxton website, but it never happened, and CBC have been asking consistently through questions backwards and forward, again with no information. GW asked "can we have a firm commitment today that those office guidelines will be posted on the Caxton Foundation website so people can know what to claim for, because I think its important, because people don't have a clue what they can claim for." Charles Lister said that he thought it was important that people were aware of the kind of things they can claim for, the guidelines for the office are simply there to indicate the financial limits that the office have before an application goes to the Trustees, but CL didn't think it was necessarily appropriate to publish the guidelines with those amounts in because that's misleading as beneficiaries could apply for more than that potentially and be successful depending on your case or less and CL wouldn't want to influence the amounts that people think they can claim, but he didn't see why Caxton shouldn't give out information about the kind of things beneficiaries can claim for. AL said she thought that was only reasonable. GW said that regarding the amounts, he was not aware of anybody that has gone over the amounts, in fact the office have to stick strictly to those amounts as maximums within the office guidelines. CL said that the point of the guidelines was that if somebody asks for something more than the office can agree to under the delegated limits, then it has to come to the Trustees, that's the purpose of them. GW said that he understood that. AL said that the principal was that Caxton need to make sure the people who can benefit, understands the sorts of things that they can claim for and she thought that was very reasonable and should go on the website. **GRO-A** made the point that if she hadn't been at the meeting today, she would be totally unaware of the funeral allowance. CL said that there were also things that automatically come to the Trustees that aren't mentioned on the office guidelines for example Caxton provide support for people who are going through treatment and facing the extra cost of treatment, loss of income etc. GW asked if Caxton make any consideration for people who have completely lost their jobs because of these viruses as they have a massive drop in income also. CL said that when Caxton are looking at the issue discussed earlier about people who are having difficulty making ends meet and having to address that need, it comes into that really because there are people who have lost their jobs have suffered really severe drops in income and that's also where a lot of debt problems have come in. CL then said that what Caxton want to do is help people get out of any debt spiral that they are in because if they've got a lot of financial commitments that their income can't meet any longer and often debt has become the only way of getting around



that, and that is something Caxton need to help to support people through. GW said for those on treatment Caxton pay £750 per month for loss of income etc, and whilst that's to be applauded, equally people who are no longer able to work have also suffered a massive drop in income and for those who are unable to work, there should be a transfer of that income to those people. GRO-A asked how the £750 figure was arrived at because some people's salaries would have dropped dramatically and should it not be fine tuned more towards loss. CL said that Caxton are trying to get a balance between avoiding too much means testing and additional requests for information; Caxton looked at one recently and to get the information would have been far too intrusive. JB said that it could have compromised other areas of their life. CL said that Caxton arrive at a figure which they felt might be a reasonable and affordable amount that would make a difference to individuals. GW said that he supposed a line had to be drawn somewhere but at the end of the day we've got one group of people who are being helped to a certain degree but people who are no able to work are not being helped to that same degree. CL said that the reason for helping people though treatment is that Caxton didn't want people not to go in for treatment for financial reasons as that is one thing they specifically wanted to avoid. CL said that sadly there are people who can't work any longer, (there are a fair few people) and went on to say that he didn't see Caxton in a position to being able to help them back to the salary and income level they were on previously, but CL realises they are facing immediate financial difficulties that Caxton do need to help with.

GRO-A said that perhaps alongside these office guidelines which you agreed should be available to everyone, can we agree that Caxton will try to hammer down some sort of timeline as well, when people can expect to get dealt with. It was talked about earlier about the committee meeting once every month to 6 weeks. GW said it says 6 – 8 weeks on the website. CL said that it is every 6 weeks. GRO-A said that hopefully the majority of cases will get dealt with, but where there are problems that result from those that need further action can we encourage Caxton to look at ways they deal with those specific cases more frequently. CL said that they already do because the members of the Welfare Committee get regular requests to make decisions via email from the office. AL said that if it was for a specific amount then she has to deal with it and said she deals with it immediately. CL said that there are cases that are urgent that don't wait for a Welfare committee meeting. AL said that as a step 1, people should have some idea about how long it might take which AL thinks that again, this is reasonable. JB said that one of the things they have been talking about in the office and which GW raised a while ago about the application process (census forms) and putting them on the website, alongside doing that they have been talking about whether Caxton could actually write a small application process with a checklist of things that people need to submit, because JB thought that sometimes it is not quite clear enough as well, and it could be published on the website as well so that people know if they want some work doing to their house or boiler, that Caxton need x number of quotes, and if they only send 1, then it can't go forward because it has to be that number of things. JB said that Caxton have been looking at how they can bring all those things together and JB thinks if

they are in a position to work out and give an indication of the kinds of support Caxton can give without going as far as publishing the guidelines which Charles said might be misleading, then Caxton could have a much more detailed set of information about what people can apply for and how to do it, on the website; although it still needs a bit of work, this is something they have already been talking about doing. GW said that he would also tag onto that the dates of the sittings of the NWC as they have never been put on the website, and again this is something CBC raised with Martin Harvey almost a year ago, with a commitment from him that he would take it back to the Trustees but it never happened. JB said that it was a problem because most grant making trusts will tell you when their next grant application is going to be. GW said "so that can go on the website then." AL said "because it needs to be as transparent as possible to people."

GW said, going back to the issue of unemployment, of the 400 that Caxton have so far, do Caxton know what the unemployment rates are within that group, is there percentage. JB and CL said that there is, but couldn't say what it was off the top of their heads. JB said that there are lots of people that are in work though. GW said that if that was the case, then there aren't that many people who have been made unemployed, so potentially Caxton could make ongoing payments those that been made unemployed. AL said that Caxton need to think about it and JB said that they can't commit to it, and that one of the real things that AL read out earlier in terms of the 'vision, mission and values' that one of the things that Caxton are really trying to do is support people into independence, and what Caxton are trying to do is give people the means by which to move on from the situation that they are in and so it's not the kind of discretionary regular payments that people are familiar with on the Macfarlane side. JB thought that Caxton really need to be clear about that. GW said that it sounds like Caxton want to create a situation where they encourage people not to be claiming from Caxton, the fact is that Government have caused these infections, people are in this situation and are facing a whole host of problems and they have ongoing needs, they are dependent and that's not their fault. JB said that there are equally a lot of people that they hear from who would rather not have anything to do with Caxton and just go to them for support when they need it and want that support and help at that time, but want to be able to move on from it and with those cases, that is what Caxton want to do to support people in that. AL said that the whole issue of dependency is something that is in need of a discussion. CL agreed with AL and said that it was clear that some people are not going to get out of the situation they're in, they are not going to get greater independence financially because of what 'life has hit them with' and circumstances and the age they're at. [GRO-A] made the point that even those who are still able to work struggle tremendously, and although people are brave and resilient, they can't maybe afford to trim down their hours to have some quality of life outside of work. [GRO-A] also made the point, what do you do, carry on working and live for 12 months or do you stop working and live a bit longer – that wasn't a choice. [GRO-A] also made the point that people can't afford some of the most basic things in life, and GW said that this dependency has been created by Government. [GRO-A] also said that the funds have got to be there for people to live a life.

**GRO-A** said that Caxton do home visits to find out what needs people have and **GRO-A** wanted to know how long it took from a request of a home visit before it would take place. JB said it depended on how urgent it was and how many other requests had been made, but would hope a few weeks, but it comes back to the issue of staffing. **GRO-A** said that some people see it as an invasion, if Caxton are sending people out to check on what they've got. JB said that some people ask for a home visit however CL said that there have been occasions where the Welfare committee have thought a home visit would be a good idea but the person has to consent and are given the option.

**GRO-A** asked how long JB/AL/CL thought it would be before the Caxton Foundation is running smoothly. AL said that it depended on who defines 'smooth' but she would certainly hope by the end of the current financial year. AL also said that she has a new set of Trustees (about 5 trustees as well) so there are 6 us brand new (including AL) as well as the 'core' of people who are left and they are quite clear at the moment about what their immediate priorities are. AL said that it was a vital thing to identify their potential beneficiaries and to communicate more effectively with the community which includes the carers, the widows to make it clear what Caxton can and cannot do, and in the meantime they will be discussing all the issues that have been raised today; the whole way in which the beneficiary community are able to access grants, AL wants to see a much more professional approach to it because it must be extraordinarily tough to have to come in the first place, and the last thing people want is to speak to a nonplussing person on the end of the phone; to make it quite clear what it is that Caxton can do and what it is that Caxton can't do. AL said that she had said to the Minister what she had thought when she entered Caxton as an incredibly part time chair which was, half a day a week, to really address the issues that had come up from the community to make sure that Caxton have a good contact with the 'Stakeholders' and listen effectively to their criticism and do something about it which are within Caxton's means. AL said that she was afraid if they have considered it and discussed it with the department, and the answer is no, the community will be honestly told 'its no and why', so that everybody understands where they stand, because that is how AL has always worked and that is how AL believes that "you've got to be honest and open" and what Caxton can't sort out or can't solve, the community will know what we can't solve. AL wanted to know what the community would appreciate in terms of communication, and also wanted to know how Caxton can make the communities life (including dependents) a bit better within the constraints that are placed on Caxton and AL said that they want to make significant progress, but she couldn't say it would be dead smooth, but aims to get a great improvement in the next year.

**GRO-A** asked if we could have an action from what has been discussed today with an indication of what is being worked on and how long they will take, so we don't rake up old ground while you're frantically trying to get things done. AL said that she would be sending us a note on the meeting together with an idea of timeframes. AL said that she would be discussing it with the Trustees anyway at the next meeting "because they understand what our priorities are and given what we have said our priorities are and what you have told us

today." AL said that they wanted a positive relationship with the community and have effective feedback and Caxton need to improve, to become something that's of real benefit to the community. GW said "talk to us when we try and contact you, because that has just not happened."

AL thanked us all for coming. GW asked if we were looking at 6 months before we meet again because there are going to be a whole host of issues that need addressing. AL said that, that is what we have agreed, but they would keep up well up to date.

Meeting ends.

**The following transcript is taken from the recording of the Caxton Foundation Partnership Group meeting and has been approved by the campaign group members that attended. It is a genuine attempt to reflect accurately the discussions which took place at that meeting.**

**Caxton Foundation Partnership Group Meeting 28<sup>th</sup> November 2013**

In attendance:-

Jan Barlow	CEO Caxton	(JB)
Ann Lloyd	Chair Caxton	(AL)
Charles Lister	Vice Chair Caxton & Chair of Welfare Committee	(CL)
David Atterbury	Thomas New Trustee of Caxton	
June Amadoye	Office Manager	
GRO-A	Contaminated Blood Campaign	(JS)
Glenn Wilkinson	Contaminated Blood Campaign	(GW)
GRO-A	Chair Manor House Group/Vice Chair Taintedblood	(DT)
GRO-A	Manor House Group	(DF)
GRO-A	Manor House Group	(EB)
GRO-A	Taintedblood	(JP)
Rachel Youngman	Haemophilia Society Interim CEO	(RY)

Apologies: Charles Gore Hepatitis C Trust  
GRO-A representative of the bereaved community

The original location of the meeting was arranged by the Caxton Foundation to take place at the Rochester Hotel, Vane Street, London however this location was not suitable as it did not have wheelchair access, so the location of the meeting had to be rearranged at short notice and the meeting actually took place at Westminster Kingsway College, Vincent Square, London

Ann Lloyd (AL) thanked everyone for attending and apologised for the inconvenience caused to GRO-A and asked everyone to introduce themselves.

AL asked if the minutes of the last meeting were a correct record (in terms of materiality) and GRO-A replied no. GRO-A raised the point that 2/3rds of what was said at the meeting wasn't included, including what was asked for carers; carers virtually don't get a mention. AL said that carer's do get a mention, but GRO-A responded with "only just, one word I think". AL disagreed and said that minutes are not of a verbatim record; she understood that the last meeting was being recorded and asked if this meeting was being recorded, if so, was everyone happy with that as it's unusual. Glenn Wilkinson (GW) said it needed recording as we have severe memory problems and can't be expected to remember every last thing. AL said it was fine and asked if everyone was happy with it being recorded. No-one objected. AL asked if everyone would have access to it at the same time; GW agreed. GW confirmed that he was recording. GRO-A asked AL if she was happy about the meeting being recorded; AL said she was used to every word she say's being recorded, and if it was for memory problems that was a reason, it's not usual practice but it is a reason

and as far as they were concerned, they want a Partnership Group meeting that worked for everybody so that they don't exclude. AL said that minutes on the other hand are a material record of the decisions or the main issues that were raised at the meeting. AL then went on to say if [GRO-A] had real problems with these it would have been helpful for [GRO-A] to have had a look at them when they were first published some 3 weeks after the initial meeting. [GRO-A] explained that with various personal issues, she didn't have the time. AL asked "to what extent is the materiality affected?" [GRO-A] explained that all it said on carer's was that *"AL advised that Caxton wishes the Partnership Group to help make the organisation more effective in supporting its clients [GRO-A] said 'we're not clients, we're beneficiaries' and AL said 'yes I know that') and develop 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 have haemophilia as well as those who did not and also includes primary beneficiaries, widows and carers."* [GRO-A] said that was the only mention of carer's in the minutes.

[GRO-A] explained that she originally applied to be a beneficiary of Caxton, and after the first letter she withdrew but after speaking with Charles Lister (CL) after the last meeting, thought it had changed so would reapply. [GRO-A] received both forms together and returned them and applied for a carer's break (it was sent recorded delivery and before 24<sup>th</sup> June 2013) and finally got a cheque for that break on the 7<sup>th</sup> September. [GRO-A] explained there were two breaks available on 28<sup>th</sup> July or 8/9<sup>th</sup> September and having telephoned the week before the holiday she was due to go on in July, she was told that she hadn't sent it in in-time to get to the committee. [GRO-A] then spoke to Roz Riley a week later who told [GRO-A] that the lady who was dealing with it had gone on holiday and hadn't left it out, so [GRO-A] had to wait until the meeting in August. Meanwhile two holidays had gone and had [GRO-A] put a deposit down on those holidays she would have lost her deposit, not only that she was unable to have a break that year. AL said that all she could do was apologise for that and that they have made radical changes to the staffing bearing in mind they have 3, because they were so dissatisfied with the speed at which the applications were processed. [GRO-A] also applied for a funeral plan and was turned down and explained that at the last Partnership Group meeting [GRO-A] specifically asked if carer's could apply and was told there was no reason why not. [GRO-A] was resubmitting her funeral plan. [GRO-A] then read out what she got back in the letter. *"I understand that Mrs [GRO-A] had a discussion with Charles Lister, Chair of the NWC at the Partnership Group meeting back in June, Charles has asked me to stress that the Caxton is able to provide support for carer's, particularly in relation to respite breaks and your application for this purpose will be considered at the next NWC meeting to be held on the 15<sup>th</sup> August. Once we have made a decision you will be notified in writing of that outcome"*. [GRO-A] explained that it said at the beginning *"although we have provided financial assistance for this purpose in the past, this has only been agreed for primary beneficiaries in receipt of Skipton Fund stage 2 payments"*. [GRO-A] asked why Stage 1 and Stage 2 are being discriminated against, widows and carer's as well. [GRO-A] said that was contrary to what the Secretary of State said in January 2011. [GRO-A] said the letter was sent by Roz Riley and that she had spoken to Roz and specifically told her what CL had said and she said that CL was due into the office on the Thursday and said she would have a word with him and would phone [GRO-A] back; she didn't so [GRO-A] had to phone Roz back. AL said she thought CL would be happy to reconsider any respite. [GRO-A] said that as Chair of the Welfare committee, Charles should know what grounds we are entitled to apply for and if

somebody asked him if they were able to apply for that, CL should either be able to say yes, or no. [GRO-A] took it from what CL said that she should have no problem in applying for a funeral plan and getting it. GW said that CBC did minute it in detail and quoted from the transcript of the 11<sup>th</sup> June 2013 PG meeting, "*AL replied "yes we've already granted those [GRO-A] asked for clarification if this was for the carers as well as for the husbands. AL and CL both said "I don't see why not."*" [GRO-A] said that she took that to mean that she could apply and will get it.

[GRO-A] said that these are the great differences we face between Caxton and MFT whereas there are huge differences in relation to ongoing payments for a widow when their husband or partner passes on, whereas someone in Caxton doesn't have that right to apply at the present time, gets no extra monies for a certain amount of time after and therefore you can see there are huge differences which needs sorting out because they are most unfair. [GRO-A] said the other thing Caxton needed to take into consideration is that it's very hard to get insurance. [GRO-A] made the point that her life as a carer is badly affected and it's difficult for her and her husband to make plans as they can be cancelled at short notice. AL said that she appreciated all that and she would like to ask the NWC to consider the general principal of carers and the best ways in which to continue to deliver a good service to them. [GRO-A] said that the best way to do it would be at the beginning of the year to say to carer's, "if they wish to apply, apply for a 'one off' grant for the year, spend it on your breaks when you can, and obviously send the receipts in when you can." [GRO-A] said it would be no good her saying, "I've got a free day tomorrow, could you send me some money and I'll have a 'pamper day', it won't work like that." AL agreed that it wouldn't. GW made the point that we seem to be going round in circles on these two aspects so there was no reason for AL to raise it with the NWC as we thought this was already done and finished after the last PG meeting as far as we were concerned. GW said CL had said to [GRO-A] last time that once the grant had been issued, it was not time limited, but are finding now that when letters are coming through that grants are now limited to 12 months. AL said it might be 12 months as Caxton only have an annual allocation, they can't promise anything else outside of their statutory annual allocation. GW made the point if that's the case, 'then tell people, don't let people find out by accident.' GW also said that they understood from the conversation AL/CL had with [GRO-A] that these grants were not time limited, but now we are seeing on the bottom of the letters, 12 months. AL asked Charles to "take it up and discuss this and then write to the PG group to tell them". [GRO-A] said "oohh some communication, that would be lovely." [GRO-A] asked if the funeral situation regarding the partners could also be discussed. [GRO-A] asked if this could be extended; "you will be pleased to hear there are people reporting some good experiences initially but they are being undermined too by not seeing things through in a timely manner, for example, people who are moving home for instance get help with setting up home costs and so on, but then they get let down with removal costs, and they've got a date when they are supposed to be moving but they don't get the feedback or response in a timely way." GW said that the letter [GRO-A] received highlighted stage 2's, and he asked if AL and CL could confirm this was also for stage 1 beneficiaries. [GRO-A] stated that when the Secretary of State announced the set up of Caxton in 2011 it was for everybody, no discrimination, but Caxton are discriminating, which goes against what was said in Parliament.

AL asked if anyone was materially dissatisfied with the minutes, could she have the amendments in writing and she would consider them whether or not they affect their materiality.

Agenda:

### **Recruitment of board member with experience of living with Hepatitis C**

AL said they hope the appointment will take place on the 4<sup>th</sup> December 2013 and that they've had a good response with individuals who are interested in this position having written compelling descriptions of how they can and cannot help in ensuring that a board member would be effective in bringing a different dimension to the board. AL said that would go on and they would circulate the name of the individual.

[GRO-A] asked if it was a member affected by NHS contaminated treatment who is applying. AL responded that there were a number of people applying. [GRO-A] asked if it was someone with haemophilia who knows the problems. AL explained that she has had long and serious conversations with a number of the individuals who would wish to put themselves forward; the thing that they all emphasised without exception was their absolute need for confidentiality so AL couldn't divulge any of this, but she could assure us that within those applicants there are people who would fulfil the criteria that the community would anticipate; she couldn't say any more without breaching it. [GRO-A] said that there was a concern that people do not want to be represented by someone who is going to speak for them who has a background of infection which is not relevant to this community. AL said that she understood that, it's a 'no fault approach' but couldn't say anymore. CL said that as a result of a discussion they had back in June they did advertise the role through the Haemophilia Society and the Hepatitis C Trust. [GRO-A] said that there is a distinction that there is a massive gap between somebody who is infected through whole blood and somebody infected through their Haemophilia and how they have lived with Hep C and their differences and how it affects them. AL said that they understand that. She also said that this person was not their sole source of advice and guidance.

### **Grant Application Process**

CL said he fully understood that things were far from perfect at the moment as there were still people who are clearly reporting experiences they feel they aren't happy with and CL hasn't had a chance to look at them. CL said that what they want to do is to have a good experience for people and want to deal with them promptly. CL said they are seeing applications coming through the Welfare Committee that they are no longer getting the kind of delays in some applications they used to have, it was fairly common, if they saw applications that had come into the office a while back they used to comment on that and ask searching questions about why that was the case. That hadn't been the case for two or three months although CL can't demonstrate what the timing is of the average application coming through, but his impression from what they see is improving although they may have a little way to go yet. CL said that they are also making sure that the office are aware if something comes through urgently that can't wait for the next meeting of the Welfare Committee (which we are still every 6 weeks) that can come to them via email for a decision and certainly between meetings they get a fairly regular stream of urgent requests that come to them and where they can, they deal with them within 24 hours within their powers depending



on the level of urgency. CL said that there was a big push to make sure that people are not kept waiting, particularly them that need decisions urgently because there is a time factor for example. CL said it does tie in with the staffing issues as well and the support behind this.

### Staffing

Jan Barlow (JB) said that during the summer, one of the things she was aware of was the things CL was highlighting when she first came in; that they were seeing application with the NWC that had got lost in the system; things weren't being followed up particularly promptly; there were delays in getting responses to people after the meetings; a lot of that was just down to the skills of some of the people involved in the team; they did a restructuring exercise over the summer which resulted in the redundancy of Roz Riley with the replacement of her role with a more Senior role, the recruitment of that was just about to start but they have had an interim person in place for a couple of months covering some of that, so thought it fair to say that the low level of complaints they used to have about delays and everything else are not happening, they are not seeing applications going to the NWC that should have gone some 3/4/5/6 months previously, that kind of thing is not happening. JB said if people apply a couple of days after an NWC meeting, if it's a routine request, there will be some delay before it goes to the next meeting because the meetings are every 6 weeks, but Caxton do now publish all the dates for those meetings on the website so people are aware when the next meeting is coming up. AL asked how long in terms of the capability of the staff before a meeting would it be sensible to get an application in. JB said it says on the website 10 days (but she would need to check); the papers have to go out, there are lots of cases every time and they need all the information in good time so that they can prepare everything and get that out for the committee to consider adequately. JB said "CL was right and that they are dealing with a number urgent emergency requests throughout the period between those applications, sometimes things are delayed because they need more information; unfortunately that is how it is, sometimes things take a while because people actually don't get back to us for whatever reason, but we are now chasing those more actively so I am sure there are some people who were still not quite getting what they want but my experience is that those things are happening, all the letters go out within the week of the meeting, so given the bits of process that have to be gone through, its not 'you apply, the next day you get a decision, the next day you get a cheque' there are stages that have to be gone through." JB said that they are in the process of upgrading their database so that they will be able in future to monitor when it comes in, when it goes to the committee, whether there is a delay before they get more information, so every stage can be monitored so that in the future, they will be able to build up some performance indicators for how long things are taking. JB said that they cannot do that at the moment unfortunately.

[GRO-A] said that the dates of the committee meetings are published on the website, but what if people are not on the internet? There will be some Caxton members who are not on the internet so they don't know. JB agreed. [GRO-A] said that for those who are on the internet Caxton will have email addresses, but for those other members who Caxton haven't got email addresses for [GRO-A] asked if they were going to send the dates out via letter. JB said that they could do that, "the only trouble is that sometimes dates shift a bit, whether every time we move the meeting..." [GRO-A] asked "so they are

not set in stone?" JB said that things happen as they get called to a meeting with a Minister or whatever it is, and they have to rearrange. JB said that they have also put more information on the website (which was originally suggested by GW) about the kind of support so that people have got an indication; the forms are up there as well so that people can download those. [GRO-A] said that they also say about more information, but when she applied for the holiday, it was a coach holiday, it was the cheapest holiday she could find, it was the only company that did that holiday, but Caxton still wrote to [GRO-A] and asked for a second quote. [GRO-A] asked why you need to give 2 quotes for a holiday. JB said that is what they have been doing unless it's an exception where you can only possibly have sourced something from one place. [GRO-A] said that she applied for that one because it was the only one that went to where she wanted to go. [GRO-A] said people are being asked for accurate figures as well, whereas other people were being asked for estimates. AL said that they have to be consistent. JB said if people are hoping to get a particular work on their homes done, say a new boiler, they normally ask for 2 quotes so that they can get value for money and then usually those things are approved on the basis of those quotes, otherwise if you're paying people on the back of the work done, that would be retrospective as things have moved they are only those kind of things in exceptional circumstances; if you get quotations as apposed to an estimate and go with that quotation, then you will get the work done unless they put a 3 month time limit on something that goes over that, but that is to JB's knowledge. JB said if there is an example of where Caxton are doing it on 'a finger in the air basis' they would be very interested to know who that was.

[GRO-A] asked how many categories Caxton had between the application status; those who are the infected making an application and the carers and dependents. [GRO-A] asked if they have two categories. JB said they treat everyone equally (AL agreed). [GRO-A] said they don't treat everybody equally. GW said he thought the problem is; the carer's and the wife's are all mixed in with the primary beneficiary and it's just fudged. "They don't know really what they can apply for and this is one of the problems." [GRO-A] said that this is why they are trying to sort out with the deeds of Caxton where the carer's and the wife's have been written into it specifically, then they can apply in their own right and is not affected or connected to the husband's status, stage 1, stage 2, on benefits and that's the way it should be. [GRO-A] also made the point that there are differences of how the two trusts operate but that there should be a level playing field. JB said that we need to bear in mind that they are two completely separate organisations. [GRO-A] said that he appreciated that. JB said that the Macfarlane Trust's funding basis has been established over 25 years, the government has not created Caxton to put alongside the Macfarlane Trust and said 'we want you both do everything and here's the funding to be able to do that.' "We are still having to apply very separately for additional funding for each organisation and so from the outside, this is slightly crazy, but that's how it is and that's how to deal with it, so we cannot automatically just have discussions about parity and we've got the Secretary of State saying there are some of those difficulties." AL made the point (unless she's misunderstood it) [GRO-A] was asking for clarification of the applicability for carer's, dependents, widows, widowers. [GRO-A] said that JB had said everybody is the same, "but Caxton do not treat everybody the same, that is a case in point. Stage 1; stage 2; stage 2 can pay for a funeral plan; stage 1 can't; carer's can't; widows probably can't. So not everybody is treated the same." JP asked if regular payments are taken into account when it comes to people being told that you can afford to pay for say a fridge,

out of your regular payment whereas someone in the stage 1 situation might be given more substantial monies towards it.

[GRO-A] brought up the issue of retrospective grants in an emergency basis and said a few month's ago they had to buy two electric recliner chairs, because the 2 they had prior to that failed, so they had to get two new ones, her husband cannot have a manual chair because he hasn't got the power in his legs and hasn't got the power in his arms. He sometimes has to sleep in the chair if he has a bleed in his arm, or he's got a bad leg whatever, so when he is downstairs I'm downstairs so I've got one. We didn't know whether or not we could apply to Caxton for them so didn't, but [GRO-A] is retrospectively now going to send the receipt off for those. AL said that she is sure that would be considered. [GRO-A] made the point that if you're ill, you haven't got the time to phone up and wait for months for Caxton Foundation to say 'yes or no' 'you need it now, not in twelve month's time, which is the experience a lot of people from Caxton are having, we have to wait for month's.' GW said this had only been changed recently regarding retrospective grants, people are being told that they are only going to be paid in the most extreme cases. GW made the point that everybody's idea of an extreme case is different. GW said that the notes from the meeting said *"AL advised she wanted the Partnership Group to help Caxton develop policy and strategies for the future"*. GW made the point that it was such a major thing to just say to everybody that the majority of the retrospective grants are going to be stopped, "we've been given no warning, absolutely none." [GRO-A] said that there had been no consultation, "we are supposed to be a partnership group, how could we be partners if we're not consulted." GW said that he first saw it on the website and that it went on two weeks previous to this Partnership Group meeting. GW said that it is not engaging with us. CL said that they never really set out to provide retrospective grants except in exceptional circumstances and if they looked at most grant giving bodies, they all say on their websites 'we don't provide retrospective grants'. CL said that there are two tests they've got in their Caxton's deed; there's whether or not you qualify as an individual which has already been talked about and whether or not you can demonstrate charitable need. CL said it was much harder to assess charitable need in something that had already been purchased and paid for and just provide the receipt; given that Caxton's aim (he hoped they are already achieving this as discussed) is they're not going to have these long delays in processing applications, then he would hope that for most things people need, there shouldn't be a difficulty in applying prospectively. CL said when they started the first year of the charity they recognised that people might not necessarily know about Caxton straightaway so there is an interim period when they gave retrospective grants on the basis that people might not have been aware of Caxton so they took retrospective grants back to the start of the charity for a brief period and where it looked as if people were going to apply for something that had they known about Caxton earlier they would have agreed a grant for, they did that respectively, since then what they have tried to do is to say, "what are the circumstances where it would be reasonable to provide a retrospective grant and some of the one's we have identified and certainly those circumstances where you don't have the time to come to Caxton and apply and get a response, even though if we responded in the quickest time possible, even if we responded within a month or six weeks, you don't have the time to wait for that so this is an urgent need. One example might be if somebody did die suddenly and you had to pay for the funeral costs, we have certainly given funding for those retrospectively. There may be circumstances where there is an emergency that we

have to deal with, something has broken down, water is pouring through your roof whatever it is, and again those are circumstances where its reasonable for people to say that there just wasn't the time to apply in advance." CL also said "the other category Caxton have identified, if something has fallen through a hole and has been sat with us for a while, somebody has waited a long time to get a response then the responsibility for that is ours." JB said "basically, if it wasn't retrospective at the time of the application, but its Caxton's fault that it has become a retrospective claim." CL said that for some things where its very clear that an urgent payment such as a funeral, it can be approved retrospectively, its taken on a 'case by case basis' and put it through the Welfare Committee and decide if somebody has got a reasonable case for making it retrospective. [GRO-A] said she couldn't see what the problem was with buying something on a credit card and then applying to Caxton to be reimbursed. CL said that one difficulty is if somebody applied for funding for a piece of furniture for example, they may have decided to go and purchase something for £2,000 where Caxton would normally only give a grant for £1,000, but you've put it on your credit card, so that then creates a difficulty because if Caxton come back and say "well actually we were only going to give you a thousand," you've then got a thousand pounds to find. [GRO-A] accepted that, she wouldn't be foolish enough to go out and spend a couple of thousand on something without getting the ok first, but said there were lots of things where you might spend a reasonable amount of money on buying say a washing machine, she would buy, spend the amount she would normally spend as being someone who hasn't got a huge amount of money. "What's wrong with doing that and putting it on your credit card?" CL said "it's a reasonable distinction that there are things for example if your washing machine has broken down, there is an argument for a retrospective grant there, if you're simply replacing something that's a bit worn out but you don't have to." [GRO-A] said he thought it was important and it was Caxton's responsibility for setting the goal for what people can apply for. [GRO-A] asked if Caxton had thought of having application forms to apply for a grant instead of just having to write a letter.

Rachel Youngman (RY) said that there were two areas here; "one is the fairness of the system, the other is the information about it as it works at the moment and there is so much confusion, "what we would love to be able to do (and I realise it's not as straightforward at this and I apologise) is just publish some kind of frequently asked questions to help people to see this in the reality of the situation because probably any involvement is very complex but if we can bring this back to some real life situations and there is one that [GRO-A] is mentioned about carer's and washing machines, just some of this, because we get asked this the whole time and we don't always know the answers, but if we could have something, it doesn't get round the issue of when something is fair, or not fair, but at least it gives people some information and some of us would welcome something like that if we are able to send that out to members, on the website and so forth and we would be happy to work with Caxton to start to draw it up with some of our members as well." [GRO-A] asked if it had changed that much between applications, "for instance if someone was to apply for a washing machine do you on the whole say you are entitled to £250 towards it or does it vary depending on their circumstances? It seems to me if it's pretty much the same amount for each circumstance, then that is something Caxton could publish and share" (the campaign group members agreed). [GRO-A] made the point that if she went to buy a washing machine, she wouldn't buy the cheapest washing machine, because that to her is a waste of money. [GRO-A] buys a better washing machine that uses less electricity (which

saves on electricity bill) but then if she were to apply, would that be taken into consideration, or would she just be given for the cheapest washing machine available which would be more expensive for her to run, and wouldn't last as long so therefore she would be applying again. GW said that he thought Caxton had maximums for what they are allowed, but they won't tell the community what they are. [GRO-A] said that surely we should know as it would make it so much easier. [GRO-A] said that the most basic things that most people do have to cough up for now and again, a new washing machine/fridge etc, how much do Caxton allow? [GRO-A] said they need replacing when they break down immediately. [GRO-A] said that she washes every day and without her washing machine, she would not be able to do that. [GRO-A] said that some people have asked why it is only a proportion of the cost that Caxton covers. "Is it only a proportion in some cases and you cover the full cost of others?" CL said it depends, how much you pay if Caxton covers the full cost. AL said "let us take back the whole issue of the information that we can use fully provide through more organisations on Hepatitis C and on our own website in terms of the sort of scope of what we are doing at the moment, the expectations of our beneficiaries etc, we have been trying very hard to improve communications, we are hugely handicapped by the fact that we actually have lost staff or just haven't got anybody at the moment to do it with the challenges of MFT and its distribution of the reserves which took everybody's time for the last few months, but it is our aim to be much more clear about what we are able and not able to do and to help the beneficiaries to attain the benefit from the charitable resource, so let us take that back and see how best we can deal with it, because you know, we don't want people thinking 'well I don't know what we're suppose to be doing and getting anxious about things and shall I buy first, or shall I not buy', just let us take that back to see the best type of information that we can produce".

GW asked if they would consider the issue of the retrospective grants being stopped as "this has been one of the biggest, if not the biggest problem that we have been dealing with on our forum, people are up in arms about it, they feel that they have had a trap set for them because they wasn't aware of it, so what I am going to ask you to do today is to consider this; reverse the decision and say to people 'we are going to look at the retrospective grants that you've already been denied and going to set a date for say 1<sup>st</sup> January 2014 and that's when it's going to apply.'" [GRO-A] said that she doesn't think it should ever apply. GW said that he doesn't really, but if Caxton are going to do it, then at least let people know, people have only been told on a website, not everybody is on the website and even those that have internet access, don't always go on it. GW said that he keeps a very close eye on it, and saw that the first time it was put on there was about two weeks ago, so people have just gone ahead, and done the usual thing of thinking 'I think that could be done under a retrospective grant' putting applications in and being told 'no'. They feel like they have had the rug pulled from underneath them. [GRO-A] said that they should be made aware that retrospective grants might not be approved, that's fair enough, but she didn't think they should be pulled away completely. There should be quite a lot of circumstances where you can go and pay with your credit card and buy something and apply to Caxton to be reimbursed. AL said that she was going to revert this to the NWC. [GRO-A] said that CBC once raised this with Martin Harvey 18 months ago, CBC thrashed this out with him about; if you can just go out and buy something you can shop around for the best deal, for example your washing machine is on the blink, you might think, Currys have got a special offer on this washing machine, but its on for 2 weeks I want to go and get one. If you

wait for Caxton to approve, you lose that offer, you have to spend more, this is the sort of thing that happens, it is the same with getting paid in vouchers. AL said that they want to be sensible and fair and open about everything they do and she would like the NWC to consider retrospection in terms of what is reasonable for the normal person when they are faced with something going wrong. [GRO-A] said that we are normal people, we've managed to budget all our lives, we are not going out to spend money unnecessarily.

[GRO-A] said that they need to be communicating this to the entire beneficiary community and encourage people to look at the website; if they could communicate at least a couple of times a year more generally, that would seem appropriate. GW said that the only way to do it properly is by letter as not everybody is on the internet. AL agreed. GW said even people that are on the internet don't always look on the Caxton website so that very important decisions such as this decision with the retrospective grants absolutely must be made clear to the beneficiary community. RY said that they have a number of opportunities with the Haemophilia Society to write to their member's so could use that opportunity, certainly twice a year they send out their HQ magazine so there are other opportunities for the Society to have an input. [GRO-A] asked if Caxton would consider letting people know that they have representative groups that they can approach so that when we come to these meetings we've got a base of opinion. GW said that a prime method of communication would be newsletters which CBC have been asking for since the beginning. AL said that she thought if the Haemophilia Society and the Hepatitis C Trust (they have been discussing that certainly with the Hepatitis C Trust and with Bernard) as a consequence of the appointment they are extraordinarily willing to help us in developing a communication with all their associates and members and that will probably be a more effective way because Caxton have got a very limited number of people on their database and that is one of their problems, they are desperately trying to ensure that they can actually get in contact with (without breaching anybody's confidentiality) the wider community that they believed (and the department certainly believed) was out there right from the beginning, but haven't been able to despite their publicity, despite everybody on Skipton being told, it still seems a relatively small number of people. If these organisations that have that wider range can help with that communication then that would be a better idea. [GRO-A] said that if they are able to agree in developing a strategy and policies it is very important to take on board what the membership groups were saying and we of course hear about people who are directly affected by contaminated blood whereas the Society have a very broad membership where the majority of the membership are really the younger generation that are coming through, those that are affected mostly by contaminants and the campaign issues they tend to come to the likes of ourselves. [GRO-A] asked if we could be part of the decision making before any final decisions are made in case we can add anything. [GRO-A] asked what was the good of having a partnership group if we don't know what's happening until after it's happened, "we should know before and then we can say either 'yay or nay'." [GRO-A] said that one of the major problems is when people are asked for proof that what they are applying for is needed because they have Hep C. [GRO-A] didn't think that she should have to prove that any of her needs are actually related to Hep C, because her financial need is related to her Hep C, its related to the fact that she has less earning power because she is not well enough to work, she wasn't well enough to work full time when she did work, and so her Hep C has caused her financial situation, why should she then have to link something that she needs to having Hep C. For instance [GRO-A]

asked if she could have help with having a tooth crowned, and was told she needed to send evidence that she needed her tooth crowned because she's got Hep C, it's ridiculous. CL said that the general issue about the question of what you are claiming for is related to Hepatitis C had already been discussed and that is something that they will no longer be asking. GW asked if they could confirm if people apply for dental work or medical treatment or whatever, that they won't be asked to prove a link between the Hepatitis C and the medical condition or dentistry that they are about to undergo. CL said that was correct although that is not the same as saying that Caxton will give a grant for everything people apply for to do with medical treatment but they will not be asking that question any longer. GW tried to highlight the case of someone he knew who had a shocking time with Caxton and who was going through chemotherapy at the time. AL said that she knew all about the case but that she didn't think it was appropriate to breach people's confidentiality. GW replied "I never mentioned the name." AL responded "but we know who it is." GW replied "if you know, then I'm not breaching the confidentiality".

[GRO-A] said that people's income are relative for example her husband could have been working and had an income of say £500,000 a year, suddenly he can't work, his income is reduced drastically. Somebody else might have been on £30,000 a year, their income could be reduced drastically; what the gentleman on £500,000 per year is used to is totally different to what the other gentleman is used to. [GRO-A] asked if Caxton would still pay to keep the upper standard of living as well as the lower standard of living. CL said that they didn't think they could. Obviously if somebody had been used to a very high standard of living that's reduced drastically then they would give them support on the basis of their need on their current income but that is not the same as supporting them to a standard that they have been used to. [GRO-A] said that their standard has been reduced because of Hepatitis C. [GRO-A] asked if Caxton see any responsibility of trying to regress the impact of hepatitis C. AL said that it's not what they have been set up to do. CL said that they have been set up to look at charitable need and that means that essentially they are addressing needs based on poverty. JP said that charitable need could be actually interpreted a lot more broadly and it could actually lift somebody not out of poverty but actually towards help maintaining a situation that is not to their detriment. AL said that fortunately they don't have anybody who has dropped from £500,000 that we know of. AL said that what they aim to do is deal fairly, equitably and on a level playing field with the charitable requirements of beneficiaries who apply to Caxton, that's what they try and do and we know what the charitable need direction is that Caxton have. GW asked what they classed as the poverty threshold. AL said that we would come back to that as it was further on.

### **Winter Fuel Payments**

[GRO-A] asked if they were going to be increased in light of the gas and electric going up by 10%. AL said that the board decided to stick with the practice of the government in terms of winter fuel payments and to send it out at £500 non means tested per household. It was discussed at length, bearing in mind that Caxton are already getting a number of requests as they usually do anyway for additional help for heating and winter payments from a number of individuals. This will be reviewed next year in the light of CPI. CL said that they are going to pay the same amount as they did last year £500 which is as Ann said, non means tested and what they didn't want to do was to

increase the amount of non means tested benefits but focus on people's needs so if people having received their winter fuel payment still needed further help with their fuel payments then that will be looked at. [GRO-A] said it would be useful if they knew that as it sounded like the committee would give you a £500 winter fuel payment it makes it sound as though that is all you're going to get. GW said that this is the first again that we've heard of it. [GRO-A] said it hasn't, people are coming forward for additional support. AL said that they were trying to get it out early this year and they can certainly put on the website the fact that this does not preclude any applications. DT made the point that these are the sort of things we need to be pre-warned about. GW said "you've just said you'll put it on the website, it comes back to the same issue, information; communication and people don't know, that's the problem, they are not aware of this so they need to be written to. If you are not going to do a newsletter then people need to be written to on a regular basis informing them of these major changes." AL said that she hoped they will have a major change to be able to communicate with them soon.

### **Regular Payments Systems**

AL said "in light of the evidence that has been coming through the National Welfare Committee we have recognised as a board that there are a number of people who are on very low incomes who actually ask for very, very little and that we should give consideration to whether or not we should apply to the Department of Health for a 'top up' scheme based on tangible evidence of low incomes for our beneficiaries. We have briefly discussed the outline policy (this is actually what we think would be good to do) for those, designed to give support to those on the lowest incomes and the Department has not said 'push off, go away' which is good, bearing in mind that the Department of Health is notorious for not having any money at all and everybody having to save governments so much per year, so before Caxton submit this case (we've done some work on what would be a sensible approach in terms of tangible evidence that's coming through the Welfare Committee, but also working with the Department for Work and Pensions with their specialist group on what's poverty or not, looking at a variety of other schemes that are being run throughout the UK, but firstly before submitting anything to the Department, we wanted to have your views of what you think the principles of such a scheme might contain so that we can incorporate that." [GRO-A] said "what you're saying is people on low benefit you would make them all a regular payment rather than have to ask for grants." AL said that they could also ask for grants, they are not precluded. [GRO-A] asked how low they would go for payments because some people are borderline, they are not on benefits but they don't get very much. AL said that they understand that. CL said that it wouldn't be just for people on benefits, it would also be for people on low incomes generally, there are a lot of people that aren't applying. [GRO-A] asked how they defined low income. AL said that's what they've been discussing. [GRO-A] said that's what she was trying to get through before when she was giving an example of someone on £500,000 and someone on £20,000; it didn't matter what your income was, when you loose your job through ill health, you've got the added expense of extra heating, food, everything else, but not only that, you've lost income so whoever is on a higher income, their poverty is relative to those on a lower income, they might have more money coming in, but they're still living in poverty compared to what they were doing. AL said that they wanted to know what we thought before presenting this case.



CL said that the key principals of the subject they have been looking at; the first is a key principle that they don't want to see any of their registrants living below the poverty line. [GRO-A] asked "which poverty line?" CL said "there is the government recognised poverty line for none disabled, that's the first thing, we have too many people coming to us whose income's of 5,7, £8,000 per year income level, which is well below anybody's definition of poverty and we want a scheme that takes them above that." [GRO-A] asked if that would include the carer's in their own right. CL said "in looking at any definition of poverty, they need to recognise it doesn't take any account of living with illness and disability which needs to be taken account of and as Ann said, we would also recognise, even if you are taking people above the poverty line that's not necessarily going to enable people to afford the sort of big purchases, the emergencies that happen to everybody, so we would still want a grant system on top of that to help people deal with those, I think its recognising that a regular payment scheme will hopefully help people manage the day to day things better." [GRO-A] asked if it would be fair to say that Caxton are seeing from people that there is a disparity between their income and their outgoings because of the impact of the disease is not enabling them to reach a level playing field and therefore that leads to more grant situations. CL said "one of the benefits of having the information we do have is that it does highlight where there is that disparity where people are happy to accept it and in some cases we've asked people to get advice from our money management, Jane Bellis, to help people get back on track." [GRO-A] referred to the minutes from February where it seemed to be suggested that you get people to alter their lifestyle to accommodate the impact of Hepatitis C as apposed to be able to rely on the Trust to help them. CL said that there needs to be a combination of both, as CL's interpretation of charitable need but what they are about is helping people to maintain a living standard of whatever that happened to be. "We're helping them to manage their lives and sometimes we try to help people manage their own finances and after that help them through the process, so, its always good that people have help rather than getting into spiralling debt and we've seen some examples of that come to us and we try to help people get out of that debt trap as soon as possible, but that isn't always best done just by helping them with their credit payments, its helping them to actually manage." GW said that this brings him to a key point he wanted to raise today. "Words such as 'offer' and 'help', 'offer of help from a benefit adviser Neil Bateman', 'offer of help from Jane Bellis, the debt counsellor'; what we've seen (and I've seen a few examples of it now) its not so much as an offer, its coming across as more of a condition and people feel that the language used in some of the letters that they are receiving is such that if you don't accept this offer, then you may be refused any further grants. Now, can we have an assurance that that will not be the case, if people (for whatever reason) decide that they would rather not use a benefit advisor or they would rather not use a debt advisor, that they will not be penalised in any way and they will not have the grants removed from them." CL said that it was difficult to give a blanket assurance on it, because they have certainly seen cases where people are getting themselves into serious financial difficulty and they have been helping them with that, help has not assisted them in getting out of their difficulties so there needs to be some kind of intervention. CL couldn't quote specific cases as that would be inappropriate to illustrate it, but there are circumstances (there aren't many of them, but a few) where people are continuing with difficulties because of that imbalance between income and expenditure, but they are more insistent on them getting some money management advice to help them out. What they are trying to do

in those circumstances is where people take up the money management advice, they have a plan to deal with their situation, that helps them then to provide additional financial assistance to help them through their financial planning. JB said "there is usually more than one option, its about the level of engagement of the individual, the extent to which the options can actually be implemented; its different in each case but its never just do this one thing, its usually a whole range of things because when people are in those situations where their income and expenditure is in a quite significant imbalance, they normally have multiple kind of debts and issues and so, its fair to say that the majority of people who they have had to work with closely on this, where we have kind of made it conditional, at the end of it, they are grateful for that support." CL said "everything is done on a 'case by case' basis; they certainly see situations where people, it's clear in some cases that we are seeing the same. Where people come back every month for something, and you see there is an imbalance between income and expenditure, you begin to sense that there maybe more problems." JB said that the frequent requests for grants are just a symptom of something much bigger, that someone might not even recognise they can get help with and that's also been the case. CL said that as a result of those interventions there have been certainly cases where people have discovered an entitlement to benefits they weren't aware of and where people develop a plan for going forward. JB said people are getting debt reduced, those kind of things, which then without intervention of a specialist they can't help them. "I think it's fair to say from our experience it's generally seen as a positive. GW said that the danger is where people are very private and they don't want people poking about their business whether it's a benefits advisor or whether it's a debt counsellor, those people could be failed because they won't receive any more help. AL said that "I don't think we've said that." GW said that in letters it is saying 'may', "that's another thing, if you're going to stop the help, then say 'we are going to stop', don't leave it hanging because then people again, don't know where they stand. If you're going to say to people 'we're going to stop your grants if you don't accept help from this person or that person, tell them, don't allude to it with 'maybe' because then they don't know where they stand." GW said 'let's call a spade a spade', not need to, not offer of help, just explain what it is. You're telling them, you're actually telling them "you will accept this offer of help or you won't get any more grants" and make it as plain as that and then people know where they stand." CL said "I feel unhappy with ultimatums that are that stark to be honest." [GRO-A] said that people just want you to be honest with them and not 'beat about the bush'. GW said that people don't know where they stand, "may, what does 'may' mean? 'you may not, 'you may have the grant stopped', 'you may not have the grant stopped'?" [GRO-A] said that she wouldn't know from one end of the week to the next what to ask Caxton for, "I know I can apply for a carer's break, and I know my husband can apply for household items, but that's it, what else?"

[GRO-A] said "there is major irony in all of this including the regular payment because the Macfarlane Trust were here 25 years ago and we said the same thing when we set up Caxton and nobody listened and it was the same. We saw improvements with the Macfarlane Trust when they finally, finally recognised and got round to printing office guidelines that stated what people could and couldn't apply for, how to claim quickly, what they could spend, and its the same with the regular payments, its roughly the same period of time since Caxton has been established that they are now getting round to talking about bridging the gap between income and expenditure that needs the support. The Macfarlane Trust was exactly the same 25 years ago." [GRO-A] said

that a lot of people have died in that time and never got the benefit of the improvements and the same is happening here with Caxton beneficiaries; they're dying. [GRO-A] made the point that the Macfarlane Trust didn't start to get the basic level of support improved to a more reasonable level until after Archer five years ago; he said "I hope it's not going to take 20 years to find similar kind of support with Caxton." AL said that they certainly hope so. AL said "we would like to know whether or not you want to tell us anything about what you would like to see in a 'top up' scheme so we can include it in our proposal, because it's important." [GRO-A] asked when the proposal was due. Al responded "fairly swiftly." [GRO-A] said that he had concerns about the regular payments in respect that we are going through a phase at the moment asking for a better settlement. "This to me sets a preference and I don't want that because we're asking for a 'one off' payment so I wouldn't want that to go forward, not yet." [GRO-A] said that "once this goes in, they will take it on board that people are happy because people have contributed towards it and this is what people want. This is not what we want." [GRO-A] said "what about those people who are living in real poverty, they haven't got the time to wait for a final settlement." [GRO-A] said that Caxton is there for them to apply for the help. [GRO-A] said that it's not working for them. AL said "can I say something political (which I would normally not do) I think the board feels very strongly about the regular payments but we do need in all conscience to recognise the evidence that's in front of us about people who are living well below any recognised poverty line and actually come to us and how on earth they are managing, I have no idea. I fully appreciate the push and certainly the publicity that has recently been afforded to you, by you on trying to get final recompense for what has happened, and I understand that absolutely, there is a huge push going on at the moment. In terms of timing, I think we need to have a discussion about timing because we would hate to do anything that makes you feel as if it would block any settlement (that would not be very helpful)." [GRO-A] thought it was important that we establish the means to look at this, 'we don't want to jump the gun'. AL's point was how long was that going to take? [GRO-A] said "could we say while Caxton is still in existence, we will agree to it, we would agree to a 'top up fund'?" AL said "we will make it absolutely clear that this is not precluding, the intention is not to preclude any discussion at Prime Ministerial level relating to the longstanding concerns of the campaign groups in respect of recognition that this has happened and an apology, and your plea over the past 30 years for true and final recognition and recompense for the damage done." AL said "we will not have a problem with that, but on the other hand, we will make it very clear that as part of this discussion that's a core principal, but I don't think that in all conscience Caxton (as long as it exists) can defer making a claim to the Department for additional resources for a 'top up scheme' given the cases that are coming through." [GRO-A] asked how they would envisage the top ups to go? "Would it be to the family or an individual top up, because don't forget carer's could have gone to work but they can't because they've got to stay at home so they're losing their income as well. I as a carer, in my own right, receive £3,083.60 a year, who could live on that, who could even exist on that because I can't." [GRO-A] said that her income is merely a state pension and she has got no other income, her husband has got a pension as well, but why should he pick up the tab? [GRO-A] agreed. AL asked if there were any other principal we would like to see considerably. [GRO-A] said it was obvious that Caxton had gone into some detail with this, and asked if they could say how far they've got and what their thoughts were. GW asked how it had come about, was it a decision that the board had made or was there any input from the DoH on this. AL said no, they've had no input from the department, she said that they have

very informally discussed with them the principal, what would their approach be “as there is no point in us putting this amount of work into doing this if they will just say ‘no we don’t want to do it’. It would be silly, so we’ve had very, very informal discussion with them about the principal of a ‘top up scheme’ on the basis on the sort of evidence that we are now seeing or able to present, would they consider any application we would make, bearing in mind the resources available to them and they’ve haven’t said ‘push off’. That has encouraged us.”

[GRO-A] asked what level they could expect the income to go up to. JB said “the most helpful thing to say is that it would; what they would be looking to do was to establish something where it was being measured against objective external measures of things like household income, and poverty so that it wasn’t just about, for example [GRO-A] knows one of the arguments that sometimes gets made against the Macfarlane scheme is that it doesn’t reflect household composition and so its how many people are in the household, is it a single person living with their parents or is it a husband and wife with 3 or 4 children, because each additional person, it causes the need for greater income in order to sustain those. There needs to be set against whatever we do, it needs to be set against some objective measure which takes into account precise household and recognised external measures.” [GRO-A] said that it seems as though there is a basic external measure that you can go to and that’s the national living wage, there is a minimal standard wage before you measure the impact on the medical need. [GRO-A] said that the living wage is about £26,000 per year, and then additional costs related to illness and so on, that gives you a minimum basic starting point. [GRO-A] said we need to stop going round and round, and decide what the threshold is. [GRO-A] said that they’re not at the moment, what they are saying is that there are a number of external measures they could look at like median household income, there are things like the Joseph Roundtree Foundation, the national living wage, “but we’re looking at external measures of poverty and household income and at the end of the day what we are able to do will be heavily influenced by what level of funding the DoH are prepared to give us. Ann said at the start that there are some principals that we have looked at which is about, no-one should be living below the poverty line, there should be some way of recognising the additional costs of living with Hepatitis C that there will still be a grant because we know that, the lowest settlement that the department might give on this where it says’ right ok you can pay everyone up to the poverty line, doing that you are not going to make everyone rich, paying everyone up to the poverty line.” AL said that it’s the ability to be independent. JB said “for people who are only on 3 or £4,000 a year that would make a significant difference for them to be able to feed and clothe themselves, buy basic necessities, everyone knows that on that level of income you still aren’t necessarily in a position to save for the bigger items when your boiler goes, or when your roof develops a massive hole again, or all those kind of things, so that’s why we would want to be having a grant system alongside that, so that when people still have those capital needs, we could still do that, so its not a ‘one or the other’; we think it’s a combination of the two, both those things are quite important. It needs to be an external objective measure which reflects the additional costs of living with Hepatitis C that still allows us to fund people for those extra capital purchases that it’s still very difficult to save for, but at the end of the day, what we are able to do will very much depend on what level of funding from the department, so we can’t really be more specific than that at this stage, that’s why we are asking you about what your thoughts are on the principals of that.” [GRO-A] said they shouldn’t take into account, a number of benefits which are related to health etc, as

this shouldn't diminish the support received. AL/CL agreed. [GRO-A] said what may outweigh certain income issues would be living with Hepatitis C which could help a lot more people than just those living on that poverty line as there are dietary needs, heat, clothes that sort of thing. [GRO-A] said that he was all in favour of someone who is on a low income getting some ongoing support, but he hoped they were going to set it at a sensible level. AL said that this was additional money they're going to have to acquire. [GRO-A] said that it would be a big help to those people who are on a very low income and I know there are a lot of people out there who don't actually apply to Caxton very much, there are some people (its human nature) who make a lot of applications and get the very most out of it they can but there are going to be some people (and I know there are people out there) who sit back, they're on a low income, they don't apply very much because they are just not that kind of person to push themselves forward, it would help those initially. CL said that that's what struck him to begin with, that what really when he first started thinking we need a regular payment scheme; it is exactly the situation [GRO-A] described. [GRO-A] said it makes things fairer. [GRO-A] said "if you are in social housing, you haven't got big bills anyway, you haven't got new boilers to pay for, you haven't got any window and doors to pay for, so what else is there?" [GRO-A] said that she agreed with [GRO-A] about the dangers of this with the department [GRO-A] said that was only his opinion), but Caxton exists anyway so why not have them dealing out their money in a different way so that it's more fair? [GRO-A] said that he had said to Ann and Charles as long as in some respects, we can make it clear that it's not something that we have thought of. JB agreed that it wasn't our idea. [GRO-A] said he has fought for so many years to get what we're getting now and then we're trying to get something better, we've never had a better time in trying to achieve something. AL agreed with that. AL and JB said that was not the intention and they will make that point extremely strongly, "the other point we will make is, its all too easy really, government will say 'ok, we are going for this, there's the poverty line, we'll go for that' we are going to press the case that we have to be more ambitious for the community because it has already been recognised by the department of health that they are going to have to fight with the treasury, that there are additional costs of living with these acquired diseases and infections so we will push all the time that we have got to be above the rock bottom, although many people are below that as well." [GRO-A] said that if they include in their application to just remind them of the grants that have been taken away from the community to which the disease of people did have now, "you know yourself we can't have certain grants including dietary things and things like that, and you're there to provide all these monies and amenities for people to get on with their life." [GRO-A] said it is quite clear as well that if the department try to take this on to form any other settlement, that settlement would have to be approved by the wider community. AL said that they need the principal agreed first.

[GRO-A] asked if the partnership group will be kept informed of what they're asking for as it progresses. JB said that her understanding is that the very detail of it, the department will want it to be kept confidential. AL said "but certainly we can tell you exactly where we have got to and the phraseology that we're using to cover the points that you've raised." [GRO-A] said "as a partnership, we have to be a partnership, it's no good you going off and doing everything and coming back and saying its all been done, because then it's not a partnership." [GRO-A] asked what the envisaged timescale was. AL said "they would need to get it in pretty sharpish because its got to be before next year's funding, for the next financial year and the way in which the treasury

sweeps up, the department's got to do its overarching additional bill which the Treasury I can imagine will look at extremely carefully because of the pressures that there are within the Department of Health's budgets and then it will apply to the Department of Health so its unlikely we will know anything until right at the end of March, if not the beginning of April really." CL said that once we know, (assuming we do get the extra money we are after) and there will be time before we can actually get the scheme running. [GRO-A] asked if this is an additional project. JB said that it is additional funding but it will all be tied up with the overall allocation, it won't be instead of. AL confirmed it will be 'as well as'. AL said "they have only done some rough calculations at the moment, but it will be considerable, we believe we will need a considerable and if this doesn't flush out the community to make applications, I really don't know what else we can do."

GW said that AL mentioned that they will be basing this on some tangible information he asked what they meant by 'tangible information'. JB said that this was the external bench mark related to some external measurements. AL said "the NWC has evidence of the cases that are coming through which have allowed Caxton to consider this which the department will know about, they won't know about the cases but they will know about the sorts of issues that are coming through and then we'll have to give them options because that is what is always expected in terms of any government grants, but to look at recognisable evidence in terms of what our limits on poverty, this, that and the other so a variety of schemes that have credibility, we don't want to just pluck a figure out of the air which we can't justify on the basis of somebody else's credited work, but we also will be, we know because our allocation is only annual that we will have to revisit this if they agree. If they agree, it's the first stage. We will have to revisit this on an annual basis anyway, and in the light of experience, what's coming through." CL said that because of the way Caxton was set up, it will have to be based on need. GW asked what it will lead to; "will it lead to people filling in census forms once a year?" JB said it will have to be decided. AL said that they would want something that reflects reality. [GRO-A] asked if they could include the increase in living costs and so on and to maintain. AL said that they can put that in. AL said that she would let us know how they get on. GW wanted it clarifying that it would mean filling in census forms once a year. JB said that it would be something like that because you'd have to be doing an assessment of people's income in order to know what you are going to top them up to. GW asked if that would still mean you wouldn't have to include DLA, Child Benefit etc. JB said that all that detail would have to be worked out when they know how much money they've got. GW said that at the moment, the forms are on the website and are still asking for that information. JB said that there was a whole load of stuff that would need to be re-looked at. [GRO-A] asked if there was any way they could make those 'more simpler' for people that have difficulties in filling out forms. JB said that before any kind of assessment that would need to be done for a regular payment scheme would be sent out to every individual that was eligible to apply. [GRO-A] said that the last health minister, Anna Soubry said that she would approach Caxton to make the form more simpler (she used those words) for the membership to fill in, [GRO-A] asked if she approached them. [GRO-A] asked why there was a stage 1 form and a stage 2 form because they are virtually the same. JB said that one of them actually asks for more detail. [GRO-A] asked why they can't just send out the stage 2 form and forget the 1. JB said that they may potentially do that and they are looking at doing a grant application form, and also getting to the point where the kind of the information about people's finances

"we will be in a position to send back to you what you sent to us last time and those that are still correct and those that need updating and those kinds of things but just to standardise things, the organisation has been going for just about 2 years now and we're still in the stages where there is progression and development and we can look back on the experiences of the last 6 months or 12 months and then do things differently as a result of that." [GRO-A] asked if the Minister had approached them. JB said that she didn't think it was about the forms, they talked about things like. [GRO-A] said "that's something else they said they would do, but they haven't done, it's just a question I wanted to know." AL said that the Minister put it in the way that she was not satisfied with the communication process and I think she will have wrapped up forms within that comment on the process.

## AOB

AL talked about the meeting that they wanted open to the beneficiary group. "In view of the fact that we will go down to 2 and a half staff, in January and February and we want to make the general forum that is open to all the beneficiaries as meaningful and as productive as possible for everybody concerned, that means, we want to have some speakers and this and that and the other, and to have views from you on what you think might be useful in that, and therefore we've got nobody in to do all the background work to help put this together as a successful day. I will propose that to make it meaningful we defer the date until the end of March and at that time we might have much more evidence and knowledge about what's going to happen with 'top up scheme'; what's happening for the rest of the year; what has happened during the rest of the year and other things." [GRO-A] said she thought it would be better later in the year because people are travelling a distance, some of them are elderly, they don't want to be setting off in the dark and getting home in the dark. AL said that was a fair point. [GRO-A] said that better weather encourages people. Middle of May was decided. [GRO-A] suggested having a different location to London for the next meeting, maybe Birmingham. JB said that they can look outside London.

[GRO-A] drew their attention to the leaflets received when we first registered with Caxton. *Number 7 Can I visit your office? Yes of course, just let us know when you want to come so a member of staff you want to see can arrange to be available, or take pot luck.* [GRO-A] asked if this still stood in terms of the leaflet. JB said that the leaflet isn't used anymore and hasn't been used for a long time. [GRO-A] said that CBC have been branded as criminals (as you know) turning up and taking pot luck, visiting the office. AL said that the two things were an entirely different scenario. The problem was the unannounced visit of a number of individuals with which the staff could not have possibly have dealt with. [GRO-A] said "we did explain when we arrived that all we wanted to do was drop in a document we had to give to you, and to pop our heads in the door and say hello. Fair enough nobody was available to actually talk to us, we popped our heads in the door and said hello and we've been branded as criminals and you've increased security measures." GW asked what does 'increased security' mean, why? "We did nothing apart from visit and introduce ourselves." AL said "we've had this conversation at least twice in the past, I have said what I said and I hoped that we had all moved on from that." GW and [GRO-A] agreed. [GRO-A] said "we thought we had moved on until we saw your minutes on your website for everyone to see, it makes it look as though we turned up with machete's and balaclava's, it really does paint us in a very, very poor light as if we'd turned up threatening violence and it really wasn't like that

at all was it, come on!" ~~oro-A~~ said "do we look like violent types?" AL said "this was a regrettable incident and it's now behind us and that's the last I'm going to say about it." GW asked if they were going to take those minutes off the website as it "brands us as completely unreasonable people and we're not having it." AL said "if that destroys a partnership relationship in its entirety then I will be willing to consider it, but actually they don't read like that and I think we've moved on from it, but the leaflet doesn't apply any more I'm afraid." GW said "that's it? Unbelievable, this isn't a partnership group meeting, it's a dictatorship." GW asked if we were 'clients or primary beneficiaries'. AL said "you are representatives of the campaign groups which is why you're here." GW asked if the people are 'clients or primary beneficiaries'. AL said "she didn't really want to have this discussion, but you entered the premises without prior permission, not for the purposes stated in there (the leaflet) and there was great concern amongst the staff endorsed by an independent who just happened to be there, and it did cause concern and the board was very concerned about it." GW said that he thought their reaction to it was completely unreasonable. GW said "also in your minutes, you (AL) made the decision apparently with the board's back up to start calling us 'clients' instead of 'primary beneficiaries' because you had concerns. What concerns did you have?" AL said that she thought beneficiaries was a demeaning word "but have listened very carefully and you are now called 'beneficiaries' because that's what you want to be called." GW said "primary beneficiaries". AL said that not all Caxton beneficiaries are 'primary beneficiaries'. GW said that he didn't think they had the authority to actually change the word because in the deed. JB/AL said that they haven't changed the terminology in the deed. GW tried to quote from the deed and said that it was an important issue and he would like to raise it. AL said "if you want to be called beneficiaries, you be called beneficiaries but there is a stigma attached to the word 'beneficiaries' and we wanted to have a more understanding relationship I think and calling people beneficiaries is rather.." GW said, "you wanted, but you didn't include us in the decision making". AL said "No, we didn't have a partnership group meeting by then because the previous Caxton administration had not chosen to do so." GW said "you have acted outside your authority, the deed says that we are to be called primary beneficiaries, you made the decision to start calling us clients, you had no authority to do that." AL said "and it has been rescinded, you know that." GW said "I don't know it at all, you've never been told me anything. I had that letter from the Minister saying that she would be calling us beneficiaries, I've never had that communication from you." AL said that they cannot disclose a private conversation with the Minister, but there we go. GW said "we've never been told from you".

AL "Have a good journey home and thank you very much for coming."



**Please Note: The following transcript is taken from CBC's recording of the Caxton Foundation Partnership Group meeting and has not been agreed with any other person and/or group that attended however this is a genuine attempt to reflect accurately the discussions which took place at that meeting.**

**Caxton Foundation Partnership Group Meeting 5 August 2014 at IBIS  
Birmingham Central, Ladywell Walk, Birmingham, B5 4ST**

In attendance:-

Jan Barlow - CEO Caxton	(JB)
Ann Lloyd - Chair Caxton	(AL)
Charles Lister - Vice Chair Caxton	(CL)
Glenn Wilkinson - Contaminated Blood Campaign	(GW)
<b>GRO-A</b> - Manor House Group	(DF)
<b>GRO-A</b> - Manor House Group	(EB)
<b>GRO-A</b> - Taintedblood	(JP)
Liz Carroll - Haemophilia Society CEO	(LC)

Apologies: **GRO-A** - Manor House Group/Vice Chair Taintedblood  
Charles Gore - Hepatitis C Trust CEO  
**GRO-A** - Widows' representative  
Dan Farthing - Haemophilia Scotland CEO

Ann Lloyd (AL) thanked everyone for coming and as there were a number of new people, thought it would be helpful if they all introduced themselves.

Charles Lister (CL) - Vice chair of the Caxton Foundation and just so you know, since we last met, I've stepped down from the Welfare committee because I have been doing it since Caxton started." Glenn Wilkinson (GW) "thank goodness for that." CL "I'm glad you appreciate my efforts, thank you." GW "Thank you very much for leaving because your existence on the NWC wasn't appreciated by the community." AL "Thank you. The person who has taken over is Richard Finlay from Northern Ireland. GW: "Is he NHS or Department of Health?" AL: "No actually - he's education". Jan Barlow (JB): "I'm Jan Barlow, I'm Chief Executive." Victoria Prouse (VP): "Victoria Prouse I'm Director of Operations." **GRO-A**  
**GRO-A**: "**GRO-A** Manor House Group and this is my third decade of campaigning and I also had a liver transplant 15 years ago and I seem to have spent most of that extra life still campaigning for something that should have been put right a long, long time ago, I've just basically wasted these steps of a gift of life I've been given. The sooner we stop going to these meetings the better." GW: "well said **GRO-A**" AL: "as you know **GRO-A** we are unable to do anything at all about that." **GRO-A** "I know you're not but that's just..." AL: "I know, we appreciate that." GW: "You have made it worse though. Glenn Wilkinson, Contaminated Blood Campaign." **GRO-A**: "**GRO-A** Manor House Group and also representative of carers." Liz Carroll (LC): Liz Carroll, Chief Executive of the Haemophilia Society." **GRO-A**: "**GRO-A** Taintedblood Chair." AL: "Thank you." CL: "I

was just going to say, to be strictly correct, we should just check that as this meeting is being recorded that nobody has any objections to that.” Nobody objected.

AL: “The minutes of the last meeting, has anybody any corrections?” GW: “Yes, **GRO-A** is listed as taking part in that meeting; he attended but if you remember the original place was due to take place at the Rochester Hotel, but it didn’t have disabled access so was rearranged at last minute at the Westminster Kingsway College but **GRO-A** had nowhere else to go so that was the only reason he sat in the meeting, he never took part in the meeting at all and he did make that clear in a letter afterwards.” AL: “Right.” GW: “Also, we’ve only received these minutes (your minutes) in the last few days. **GRO-A** “I only received mine Saturday.” GW: “We’ve not really had chance to go through them in any detail.” **GRO-A** “if possible if we were to have a copy of the minutes ahead of the meetings it would give everybody a chance to go through them.” AL: “absolutely” **GRO-A** “also, if we could also have a list of action points as well as earlier minutes so that we’ve got some continuation if either one of us can’t attend and it will also help us to judge how well the whole group is performing; do we actually achieve anything or are we just repeating the same things again and again.” AL: “Thank you **GRO-A** “We have a number of matters arising.” **GRO-A** “There was one last thing, a correction on the conditions of your minutes. Also discussed was the potential for ongoing payments. We also discussed what we thought the levels of payments should be were we able to achieve what we wanted and I’d suggested that it should be connected with the national averaging wage which is approximately £28,000.”

AL: “We have a number of matters arising. The first one is the recruitment of the Board member of experience of living with Hepatitis C. Margaret hoped to be here today but she has unfortunately not been able to do that but she has allowed me to speak on her behalf about how she met the criteria for a Board member with experience of living with Hepatitis C. She was infected by a blood transfusion on the birth of her first child in 1987, **GRO-A**

**GRO-A**

**GRO-A** Liz Carroll (LC): “What was her name?” AL/GW: “Margaret Kennedy.” AL: “The second matter arising was you wanted to raise...” Jan Barlow (JB): “Yes, that was just to introduce Victoria today. I reported at the last meeting that we had instructed the Welfare team and Victoria is appointed following that. We also have a new finance manager starting next week. I think it’s very rare that people speak directly to the finance department but in case you do the new finance director is called Joyce Materego and she will be joining us on Monday.” GW: “Can I just cover a point about Margaret Kennedy? This was in an email, a latest email I sent to you on 23<sup>rd</sup> June 2014 (it will probably be best if I just read it out) *‘We note Margaret Kennedy is now listed on the Caxton Foundation website, could you tell us if Margaret Kennedy has been given a specific job title or role, because there’s nothing listed on there. We note in Margaret Kennedy’s description that she has a long history within the NHS, as you know the community’s*

*understanding and expectation was that this new board member will be an individual directly infected or affected from within our own community as we felt that the board consisted of too many individuals with history within the NHS or Department of Health.* We already know now she is an infected individual, no disrespect to this lady but she is still NHS and we did specifically request that whoever the individual was, it was somebody from within our own community who didn't have a connection with the NHS or Department of Health." AL: "As you know, your society (Haemophilia Society) and the Hep C Trust helped us very much with the recruitment of the individual, we actually could not restrict to any specific or actually remove any specific individual because they happen to work in a particular field. What we had to do was to adjudge the individual's capability and we had a number of people who applied for this position to the most able of the individuals and the most able in terms of their understanding, appreciation and personal experiences in dealing with the infection and it is on that basis that she was appointed." [GRO-A] "it's very good that she's got experience of Hep C but you understand the suspicions that keep creeping in here is that it's just such a coincidence that there is so much of a connection with the NHS or government whenever there's involvement on the board or a new appointment and given that those suspicions exist, I think it is something you should be bearing in mind and you could have done during the interview process." AL: "I don't think I was quite so acutely aware of the real suspicion that is within but I think I only really became aware of the acute suspicion after our last Partnership meeting." [GRO-A] "I thought you would have noticed from previous PG meetings as well. AL: "not necessarily, no, they haven't been specific about anybody from the health service being totally outside." GW: "Our campaign group's made it abundantly clear and I would have real concerns if you didn't realise that, that's a very basic fact that you should have been aware of right from the very beginning." AL: "Ok." [GRO-A] "getting away from the NHS, I brought this up before, the Haemophilia Community have different and more exacerbated problems than the whole blood community, wouldn't it be fair to have somebody who knew what it was like to actually live with Haemophilia on the Board as well? They could given an input on the problems of haemophiliacs are like because haemophiliacs have not only got the hepatitis C problem, they've also got the bleeding disorder which makes life triply difficult." AL: "It is certainly something we could discuss with the Board and consider." [GRO-A] "And also somebody who has knowledge of living on state benefits because reading the board members, they are all from highly paid jobs, they haven't got a clue what it's like to on a Thursday night, know that you do not get paid until tomorrow when you haven't got enough money to put in the electric. They haven't got a clue." GW: "Well said." [GRO-A] "They also tend to have been infected with Hepatitis B as well as other things which also exacerbate the liver damage." AL: "Certainly I shall report that back to the board and will take it up with them, thank you."

[GRO-A] "How many office staff do you have in total now and are they all full time, part time?" JB: "Caxton has the equivalent of 3 ½ staff in total. In the offices we have 9 staff and they work across 5 organisations – Macfarlane, Skipton, Caxton, MFET, Eileen Trust and people's time is split across those so we don't have 3 ½ bodies times is only taken up with Caxton. Nicole who you've probably had contact with on the grants side, she works solely for Caxton but the other people like myself, I work half time for Caxton and half time for Macfarlane, Victoria does the same, the finance manager's time is split between all 5 and so it goes on, so people are kind of split across the organisations, but in total it comes to about 3 ½." [GRO-A]

“There was a limit wasn’t there?” JB: “Yes, it’s capped at 12 and I think including the Eileen Trust person there are 10 bodies.” [GRO-A] “So 10 bodies, so it’s not the actually the amount of posts you have got to fill, it’s actually the number of bodies, so if you half each doing part time, that would take it up, whereas you could have say 12 full time staff?” JB: “Yes.” LC: “So they don’t do it on a full time cover?” JB: “No.” LC: “That’s crazy.” [GRO-A] “Is that not something you can challenge?” JB: “I think that’s been the case that it’s been challenged before and when Caxton was introduced additional staff were allowed at that point and I think that was when the cap of 12 came in.” [GRO-A] “Wouldn’t it be better from your point of view then not to take on part time staff, but literally to employ full time staff and then you would have a higher number?” AL: “But most of them are full time, but they’re split between the organisations.” JB: “But it wouldn’t make sense to have, there’s only so many ways you can do it and there are efficiencies to sort of the knowledge and everything that people have so we wouldn’t get very far. The majority of people are full time to be fair, I think we have the finance assistant who is part time, and the person who works for the Eileen Trust is part time, I think everyone else is full time, so it wouldn’t really make an awful lot of difference.” [GRO-A] “It sounds like there’s ‘spare capacity of staffing’ when they’re struggling, it doesn’t make sense not to be using that.” LC: “When we spoke a while ago, you had some vacancies, are they all full now?” JB: “Yes.” [GRO-A] “Would it not make sense to have dedicated staff at the Caxton Foundation, that way when we phone up, we know exactly who to ask for, who to speak to and who deals with what.” JB: “Well there is one dedicated member of staff across 3 ½ people, that means that 2 ½ people’s time is split doing all the other functions, we just don’t have the funding at the moment to be able to do that.” [GRO-A] “How many quotas are Caxton were allowed?” JB: “It’s never been set down in that way but the understanding is that those other posts would be split across the other 4 organisations as well.” [GRO-A] “So basically, the Caxton beneficiaries have got one named person to speak to if they want to speak to somebody.” JB: “Pretty much, but so does everyone else, it’s the same for MFT, much the same for Skipton, the same for Eileen Trust, MFET.” LC: “Is it sort of the officey functions are often shared so finance, admin those sorts of things and there is speciality bits of knowing the trust is the bit that has one person, is that how it’s split?” JB: “Yes, pretty much.” GW: “This is an issue that we’ve raised several times with our MPs and the APPG, but what do the Department of Health say when you raise this with them, about this cap? Do they give you a reason why they put a cap on you?” AL: “They haven’t given a reason, that was the cap that was set and we were very mindful of the fact that we have to balance the proportion of our resources that we spend on staff, we’ve been very concerned that actually, it might be too much spent on staff, so we have tried to ensure that we have stayed within our cap, but the department is aware that there have been performance issues which fortunately, are becoming much better, much much better, and when we have our review (and we haven’t got a date for that yet) we shall be raising this again, because we are also seeing an increase in the number of potential beneficiaries that we are receiving enquiries from so that would form part of the evidence that we will provide to them.” JB: “I think the only thing to say at the moment, there is no indication the department would be giving us any more money, so any more that we spent on staffing, would effectively be taken off the budget for charitable grants and stuff.” LC: “Do you have ‘one pot’ if you like, so when you receive the money, this is what you’ve got for the year; staffing and grants, and it is one pot, it’s not split?” JB: “Well it kind of is split in terms of we have to be specific about the staffing costs and that’s kind of separated out.” [GRO-A] “This is one of the

deteriorations in the way that the department have treated the trusts over the years because at 'once upon a time' Macfarlane Trust used to get that recognised and separated out so that their admin costs were paid separately to the amount they received in grants, in the end they managed to roll into one and told them they've got to make savings even though they were telling everybody else "oh there's no reason why the trust can't be more supportive." LC: "is there anything you think we could do in terms of support for the fact that actually it takes quality staff to run a trust well, so is there anything so the APPG could be the secretariat and as the society we could separately write to the Department of Health, is there anything we could do that you think would be useful and helpful wont do any harm?" JB: "I don't think it's about quality staff." LC: "No, no, no what I'm saying is that to be able to have good quality staff you need to employ them you need to fund them you cant just pick someone off the streets." [GRO-A] "Without being over exuberant do you have an idea of what you'd really like in place if you didn't have to work to account and all that, to run it efficiently." LC: "Without being stretched." JB: "Not off the top of my head, but definitely more than we have now but it comes back to the issue of funding that potentially any money more that we spend on staffing would be money taken out of the charitable pot and I've never heard any support for doing that." LC: "If we were able to explicitly write and say this should not reduce the amount of money that is paid (I know they might not listen) but actually the more people who say what your doing is wrong you need to rethink it the stronger it is and we could certainly do that and I can talk to the APPG about actually maybe some of the problems, people experiences, that staff are pushed, there isn't enough time for them to necessarily work in the way that they'd want to, if that would be helpful I don't see any reason why we shouldn't do that. "JB well maybe we should think about all that." [GRO-A] "If you're pushing and we're pushing then why shouldn't we push to get the admin costs separated back out again?" LC: "Exactly." [GRO-A] "It would make far more sense.

[GRO-A] "Can I ask what the budget is for this year?" AL: "What for staff?" [GRO-A] "For both." AL: "Oh, for both." JB: "The total of £2.38 and I'm afraid off the top of my head I can't tell you what the admin budget is for staffing, it's about two hundred thousand?" GW: "2.38 for Caxton specifically?" JB: "Yes, 2.38 total allocation." [GRO-A] "And how much has been spent have you any idea? AL: "Yeah, hang on." JB: "Yeah we do but I haven't got those figures with me." [GRO-A] "Well I'll get onto Andy Burnham on that one anyway." LC: "So Jan if maybe we liaise about and then you as a group liaise about actually what is it we think would be a reasonable ask, that might be useful for you and for the beneficiaries to receive what they think would be right and come somewhere in the middle. Would that be ok?" GW: "We've got to be careful about what we ask them for; really what we want is for Caxton to be shut down." AL: "Yes we know that." LC: "Well there's something about while full and final compensation is negotiated and agreed there needs to be support in the meantime." [GRO-A] "Yeah, but that's providing the support is being given and it's not being given." GW: "We had a similar conversation at the last PG meeting about the way forward and asking for these on-going payments for people who are below the poverty line, I think [GRO-A] mentioned the point that really we don't want to be going down that road because really we want rid of this failing organisation, this government quango, so to some extent we've got to be careful about what we ask for. By the sounds of it this business case has been put forward to the Department of Health and it's been thrown back in our faces so what is the point?" [GRO-A] "Could we have a copy of that business plan?" [GRO-A] "Yeah, have you got Department of Health

clearance now? Can I ask why you needed Department of Health clearance?" AL: "Because you always have to have clearance if there is a business case that the Department of Health is considering at any time, it remains confidential at that time until they've made a decision." [GRO-A] "Ok, but after they've made the decision you're not beholden to them to..." AL: "No, but it is courteous to tell them." [GRO-A] "Could you send me a copy?" AL: "Of course." GW: "Have you got specific reasoning from the Department of Health as to why they've refused it?" AL: "I can read it to you if you wish." [GRO-A] "Have you considered circulating the business case to Alistair Burt and the APPG with that information that it was turned down to so that they understand what you're asking for?" AL: "That is part of our submission." JB: "But in terms of Alistair Burt, his work is about a final settlement, it isn't about the funding that we get out of them." [GRO-A] "Yes, but he's also building a case as to why, what we've got at the moment isn't adequate and it isn't working so it would help." LC: "He's working with the APPG so on the two arms this isn't good enough which is why you need to do something about it." [GRO-A] "And also I know the Shadow Secretary of State For Health is important." AL: "Would you like me to read it through? *'Ministers have decided that this is not the right time for an uplift in allocation whilst they continue to consider how best to address the range of issues about the system of support available for those affected by contaminated blood many of which were highlighted during the Westminster hall debate on the 29<sup>th</sup> October.'* Then it says *'we haven't been able to confirm our allocation yet at the moment I recognise that the decision not to increase funding will be disappointing news for the Foundation'*." LC: "I wrote to the Department of Health team as well to say could you explain why you would say no and I got basically the same response, 'the Minister felt it wasn't the time', so I went back and said 'is that because your looking at full and final compensation' they said 'we can't comment'." [GRO-A] "Anna Soubry said in one of the meetings we had that she didn't see any reason why we couldn't be making adjustments to the scheme at the moment to help it until such time as that process was complete." AL: "Well, that's our position."

#### Winter Fuel Payment

Ann Lloyd asked Jan Barlow to make a statement on the winter fuel payment. JB: "Just to let people know and confirm that the board has agreed to make a winter fuel payment against the same level as last year and as last year it will be getting paid in November. We had a lot of positive feedback about paying it that early compared with the previous two years when it hadn't gone out til about March so we're planning to keep to that timetable." [GRO-A] "Can I ask, if you're going to review the decision not to uplift in line with inflation, what happened on that review?" JB: "I think we are aware that the payment we make is considerably higher than the one the Government makes so kind of in excess of that Government one, so I think the board decided that in the light of the other funding priorities this year that it needed to be kept at the same level." AL: "But this is an issue that's reviewed every year." [GRO-A] "I was gonna say, it did go to review though because that was mentioned at the last PG meeting." AL: "We had some very long discussion about winter fuel payments." GW: "There was an issue about previous winter fuel payments if you remember regarding people having to fill in census forms." JB: "That wasn't done last year and it won't be done again this year." GW: "So there's no conditions attached to that now?" JB: "People have to be registered with us and they have to have done Part A because that's effectively our detailed registration but we didn't ask people to fill in

part two last year like we had done the year before, so we will just continue that practise going into winter fuel payments. They only thing we will be doing this year is, because it's been a while, we will be asking people to re-confirm their bank details, that's the only thing we will be doing." [GRO-A] "Is that your annual census form that you do with the winter fuel payment at the same time?" JB: "We don't do an annual census in the way that the Macfarlane Trust does." [GRO-A] "You don't, so that essentially is your census as such, just to confirm that people are still alive and with you?" JB: "When Caxton started before I joined, when people registered they had to effectively fill in Part 1 and Part 2, but what you'd recognise as the MFT Annual Census, even if they weren't going to apply for Grants or anything else, we decided that until people needed to, you know, wanted more from us, if you like, that all we needed was the basic information about them and we didn't want to make people fill in that Part 2, so we moved away from doing that, but just for financial reasons and audit reasons we need to just reconfirm people's bank information before that payment is made." [GRO-A] "Is there a requirement for you just to confirm that people are, sort of, effectively still on the book annually, or?" JB: "Well we need to know that if we are effectively paying something into someone's bank account, that that bank account is still valid, that someone is still the owner of that bank account, so we just have to do that for audit purposes." [GRO-A] "My bank account details aren't registered with the Caxton, I asked to be paid by cheque, so I'm not officially on your census." AL: "Well as long as they've got those details..." [GRO-A] "Oh, they have; they've got my husband's details and his bank account." [GRO-A] "So you don't have to confirm that you're still with us..." [GRO-A] "I think they know that." JB: "But also we make those winter fuel payments to primary beneficiaries and widows so the winter fuel payment wouldn't be made to [GRO-A] directly as a carer, it would be made to her husband." [GRO-A] "But he doesn't have to confirm anything either way if he's paid by cheque?" [GRO-A] "No, I'm paid by cheque, it goes into his bank account, I won't give them my bank account details." [GRO-A] "So, just with my MFT hat on for second, I was just wondering, I was just trying to understand the legal side, because we're told with MFT that you have to fill it in, it's a legal requirement." JB: "But its not for MFT that you do it [GRO-A] it's for MFET, and people who are in receipt of Skipton stage 2; you have to do it for Skipton as well, its done in about March if I remember correctly; every March time, people have to confirm their bank details are still valid, it's just a one sheet of paper people get." [GRO-A] "But the MFET thing, we have quite a simple thing don't we that we just have to sign and send back, but there's the larger census that's usually kind of slanted as if it's MFT." JB: "The bigger census is MFT but the confirmation of bank details is MFET and Caxton for the winter fuel payment, it would be similar to the MFET/Skipton stage 2 bank forms." [GRO-A] "Ok, so actually, legally there is no need of almost for that MFT larger census is there?" JB: "There is because the discretionary payments are based on it." [GRO-A] "Because of the 'top up' payment?" JB: "Yes." [GRO-A] "Ok, I understand the distinction." [GRO-A] "My husband doesn't get a 'top up'." AL: "Are there any other matters arising?"

GW: "Just a couple of things, Caxton numbers there is a figure approaching 800 previously do you have any idea of what it is now and whether it is expected to increase?" AL: "It is increasing, Jan have you got the latest?" JB: "It is constantly increasing but I'm afraid I don't have them stats with me." AL: "We'll put those in the, we'll email everybody." [GRO-A] "Can you write to me as I'm not on email?" AL: "That's fine." GW: "Because originally there was expected to be about 3,000 applicants come forward." AL: "Well, 1500 we thought." GW: "Was it 1500?" AL:

"1500 yes." GW: "I don't assume its anything like that, probably 8 or 900ish?" JB: "It's not as many as 900 at the moment, but it went up by about 150 last year." GW: "Really?" JB: "Yes." GW: "Were those predominantly, would you know off the top of your head whether they were predominantly haemophiliacs or people without a bleeding disorder?" JB: "I wouldn't be able to tell you off the top of my head, no." AL: "But at least, you know, more people are coming forward which is what we wanted." LC: "And is that people are finding out that you exist do you think, is that mainly what it is?" JB: "Yeah, and everyone has to have had a Skipton payment before they can register with Caxton, so there's a piece of process that Skipton always does and I know that they have had a constant stream of people still coming through, so it's probably as a result of the information that people get through that., but people also just randomly find out, but its basically as a result of Skipton."

[GRO-A] "I was going to ask about the numbers, your numbers are they just beneficiaries or are they a mixture of family?" [GRO-A] "Are they only just primary beneficiaries, carers, children." JB: "The people that are registered are primary beneficiaries and widows. Children effectively come through the family one way or another because they're dependants and on the whole most carer's come through that route as well." [GRO-A] "Well I'm sorry, but that's wrong. Carers should be considered on an individual basis, I am an individual, I am not my husband and I wish to be considered as an individual with my income separate from my husband." JB: "But not everyone takes your view." [GRO-A] [GRO-A] "But, can I then be treated as an individual, not ...?" AL: "You are, you are." JB: "But you are treated as an individual." [GRO-A] "No, I'm not." JB: "In what sense?" [GRO-A] "Because you've just said I have to come through my husband." JB: "No, what I am saying is, I said on the whole, carers (children definitely come through their parents)." [GRO-A] "Obviously, yes." JB: "And on the whole, carers choose to come through their partners, if they don't we have a small number of carers registered separately." [GRO-A] "Well how do I know whether I'm registered via my husband or whether I'm registered separately? I didn't know anything about this until today." JB: "Well now you do know. It doesn't affect your access to grants does it?" [GRO-A] "Well, it can do." JB: "But it doesn't." [GRO-A] "Well, I can't put in a grant because the only grant I need to put in for is basically if I want, say a couple of pamper days, if I get time, or a holiday. Now, this year, I can't put in for a holiday because my husband's waiting to go into hospital so I don't know when I will be able to go, so therefore I can't send you 2 estimates and because I don't know where I'll be going, when I'll be going, so therefore I can't claim. I can't put in for a pamper day because I might be able to go, say next Thursday, it will take me 6/8 weeks to get the funding to go for it, I can't do it, so what's the point? The Caxton does not work for a haemophiliac's carer." GW: "That's true I'm afraid and I'll tell you why. Because if an individual, and you know that I'm in this situation where I have refused to jump through all your hoops, that then immediately cuts out my entire family; it cuts out my wife, cuts out my son and it cuts out my daughter, but on principle I won't do it, I won't jump through your hoops and that cuts them out totally and I think that is so wrong. So if somebody is in my position where they just flatly refuse to do it, and there might be some other people who just can't, because I know there's people who can't bring themselves to actually go through this monstrous process, they just mentally can't do it, that again immediately cuts out all their family members, and its wrong." [GRO-A] "But for me as a carer of a haemophiliac, the Caxton, your set up is not appropriate, it is too time consuming and by the time I've jumped through the hoops, I might not be able to do what I wanted to do like last year when I



applied for a holiday. It took that long I couldn't go on the holiday I wanted because it was no longer available so I ended up having to settle for second best. Is that right that I have to do that? And I'm just one carer, the other carer's I have spoken to have all said the same. We are not considered." AL: "Then I think we need to clarify the situation relating to carers and advise them accordingly." [GRO-A] "But it's also your claims process, you have to put in your claim 2 weeks before the committee meets, you then wait for the committee to meet, you then get a response within another week (which is 3 weeks), you then, in my case last year, I got a form to fill in to say that I would use the money for what I'd intended it to be used for, I had to then send that back, which took another few days. By the time I'd get the cheque, it would be 6 weeks from sending it in (that's if it was agreed) to receiving the money. People haven't got that time to waste Ann. If I put in for a claim, I need to know that within a week somebody in that office can say 'yes or no' and send a cheque out. Because of my husband's illness." AL: "We understand that." [GRO-A] "Yeah, but it's not just me it's happened to, it's other people. The Caxton isn't working. How many times do we have to tell you? You need to change your process because it is not working for the beneficiaries and I have got permission from this lady to bring these letters. She applied for grants; she is a 79 year old widow who had a ten hour operation to have a colostomy bag fitted, she applied for a grant in May for a walker (a walking aid), to have a fan fitted in a shower because she can't bathe, and the fan broke, and obviously she couldn't use the shower without the fan (it still hasn't been paid); for help with her MOT that she got last year; none of it as to now, has been settled and I have her permission to show you these, or to give them to you (you can keep these I've got copies) and it still hasn't been settled; its not going to the committee til August because some of them are retrospective, and I think, when you read that. Also, she sent in all the receipts, everything that was required with her application letter; you've lost them." JB: "Allegedly" [GRO-A] "Now you're asking a ... allegedly.... are you calling this lady a liar? JB: "No, but..." [GRO-A] "But they all went with the letter." AL: "Can we deal with this outside this meeting please? It's an important issue." [GRO-A] "It is an important issue." [GRO-A] "It is an issue, what it does reflect though is that there's not an appreciation for what it's like to be in that situation and we do need that reflecting better." [GRO-A] "But I mean, every time, my husband applied for a holiday in January, we paid for it because it was the holiday he saw that he needed. He'd lost his father, he'd had operations, he was waiting to go back in hospital, he really had a bad six months and because we saw the holiday that we wanted and because of our previous experience he paid for it and then we applied to the Caxton and we were told because it was retrospective he couldn't have it; we appealed and we were told exactly the same. Now, because of the experience I've had with mine, that was why he did it and when we wrote the appeal letter that's what we put in it and it was still rejected. It is not working, it's not working for me, it's not working for my husband and other beneficiaries it's not working to. Everybody you speak to, you say the Caxton foundation; oh I don't really want to go to them, I don't want to beg and I don't want to..." AL: "Yes, you've said that before." [GRO-A] "But it's still going on and after nearly three years. Why is it going on? Why are we being made to feel the way we're feeling?" GW: "And this lady's example is nothing unusual, it's been going on since the very beginning." [GRO-A] "I mean I've given copies of that letter to my MP and he has read them" GW: "One way around it might be to simply make the widows and the carers primary beneficiaries, do you have the power to do that?" JB: "No we don't." AL: "No, I'm afraid we don't." GW: "It's not what it says here in the Caxton Trust deed; I'll read it to you, it says *The Trust deed shall have the power*

*with the consent of the founder to add individuals to the class of primary beneficiary and to alter the definition of the excluded persons'* JB: "But what it means is to add people to the definition is about who is registered as a primary beneficiary." GW: "Well register the widows and carers as primary beneficiaries." JB: "The primary beneficiary is those who have been infected." GW: "Yes but what I'm saying is that this trust deed....." AL: "We cannot alter the law I'm afraid Glenn." GW: "I'm not asking you to alter the law, it says here in your own Trust deed on your website that you have the power at page 3 item 5.3; to add to the list of primary beneficiaries. 'The trustees shall have the power with the consent of the founder (I assume that's the department of health) to add individuals to the class of primary beneficiary therefore....." [GRO-A] "That's down to how you read it in the definition." GW: "It seems pretty clear to me...." AL: "Let's just cut this conversation because there are important things getting lost. We will certainly provide you with the legal advice on that one and as for [GRO-A]'s concerns, they're very, very important and I'm going to ask the NWC to assess her concerns about, I know we've speeded up the way we manage our requests for help and assistance but nevertheless they are already looking at the office guidelines with a view to increasing them, because they go through them at this time, and to come back to you about that.

[GRO-A] "Is there progress on this intention to have printed office guidelines that everybody can look at and know clearly what they are entitled to or?" JB: "But there was never, I don't think there was ever any agreement to do that, we talked about that previously." [GRO-A] "In the previous PG there was." JB: "Not to, I think if we look back at the minutes it was about, we talked about those limits and it was that the limits were just for office guidelines so they are not the limits are what can be approved by the staff and which have been agreed by the board and if people want more than the office guidelines limits, people can go through the committee to apply for that. So the limits would kind of give a false impression of what's available so we never discussed an agreement to do that [GRO-A]." GW: "I think we as a Partnership Group are saying that those office guidelines must be put on the website because people need to be aware, they need to be very clear as to exactly what they can claim for and the amounts they can claim for. I understand this is being done for the MFT. Can you confirm that [GRO-A]" JB: "No it hasn't." [GRO-A] "they did in the past and they have taken it away, likewise I think they are looking at reintroducing it or, (they are always looking to reintroduce it but)." [GRO-A] "But to be honest I don't know what I could claim for and neither does my husband." LC: "I was just going to ask you that, we often get calls from people saying 'I don't know what I can apply for and what I can't. It maybe on the website, but it would be helpful if there were maybe really clear guidelines of who can apply for what, whether you've updated them." AL: "Certainly the annual report was clear about the sort of grants..." LC: "Just like a 'fact sheet', almost a fact sheet of, this is who can apply; this is how you do it, how long it will take..." [GRO-A] "And if there's something that's linked to means testing, or there's..." AL: "but certainly the website is being revised anyway so it needs to be clear." [GRO-A] "But you would have a paper copy for instance if someone was the ring the office and within that you can state (as Jan was explaining) that the limits or the amounts available may vary depending on circumstances or means testing whatever, but people would understand it then if that was just stated." JB: "But the office guidelines, there are things that for example aren't in office guidelines which can still be considered by the committee." GW: "But that could be made clear on the website, people could understand that if the details were put there. Can you confirm that the

office do have a set of guidelines which list specific items be it washing machines, beds, decorating, house moves etc etc, they have a list of specific items and the amounts against those items. "Do you confirm that?" JB: "Yes". GW: "so all you have to do is simply put that list on the Caxton Foundation website, its simple and it could be done tomorrow." LC: "The other thing I wonder if it would be helpful if you could do, is to have something about how decisions are made? So like a 'decision making flow chart'. There may be something (and I don't know), but it's the sort of thing that we get asked actually, you know, how do you make decisions and my answer is "I don't know." But I think that sort of flow chart would be really helpful." AL: "At the last meeting, Rachel said that you were getting a number of questions and you would like to publish some fact but she didn't get back to us." LC: I think that's because she was an interim." AL: "I understand that, so it would be really helpful if you could liaise with Jan about what would be useful information to go on your website as 'you get these queries'." LC: "It is frequently asked questions of things, and 'what you can apply for?' 'who can apply?' 'how long it takes?' 'if you can give guidance on the sorts of amounts and where it's flexible and where it's not' 'can you repeat applications?', those sorts of things, just so people are really clear I think would be really helpful." [GRO-A] "Like for instance with the treatment payments that are available, is it the same whether it's the first time you have treatment, second, third, fourth whatever, what sort of things do you need to provide?". AL: "Fine, because we do need to speed up the process although we know that the process is getting quicker but nevertheless I do want absolute clarity so that people can access..." [GRO-A] "Who set these office guidelines up in the first place?" AL: "I should think the NWC did that, that was prehistory." CL: "They started off, I think we took the office guidelines the Macfarlane Trust used and adapted them." [GRO-A] "I find it absolutely pathetic in a way that it's not unreasonable for somebody to come to you and ask for a washing machine for example £250, which is not a lot of money for a washing machine and yet there are people who have been given grants for £150 which I do find insulting." AL: "The NWC is reviewing the office guidelines at the moment." [GRO-A] "It is crazy that, you know, we're not talking London prices here, we're talking Argos £250 for a bloody good washer. I know you can pay £500/£600 for a Bosch, or whatever you want to do, but to be insulted by getting a cheque for £150, I do wonder like the rest of us 'what was the Caxton set up to do?' [GRO-A] "Exactly". [GRO-A] "That is absolutely crazy". AL said "they are reviewing them, we've asked them to review this so they will come back to us with their recommendation." [GRO-A] asked "Is there a point at which your income, and it occurs to you that people should be able to afford all of these things, then I think people would need to know that as well, that would be useful." AL: "I don't think we make that sort of judgement actually." [GRO-A] "So you don't make that judgement?" AL: "No, not as a board, certainly not." GW: "There is some minutes on the Caxton website that list a figure of £14,000." [GRO-A] "So they think you can manage if you've got that sort of income? CL: "Just to say, that was very early days when we were not sure how many beneficiaries were going to come forward and there was a question of whether we needed to give preference to people on lower incomes and if we were going to have that kind of cut off around lower incomes, what that should be and we decided to take the 60% of medium income definition of poverty, but in actual fact, we never really used that £14,000." [GRO-A] "You were look at a redefinition of the disabled poverty line as well." CL: "Well exactly, because the 60% doesn't take account of illness or disability. AL: "That's right." [GRO-A] "Has that happened since, or are you about to tell

us something on that?" AL: "Anything more on matters arising? Can we go onto the regular payments system please?"

#### Regular payments system

AL: "Subsequent to the department of health stating that they couldn't provide us with the resources to actually undertake the scheme that we'd asked for and the board discussed this at great detail because they were very concerned that the information arising through the NWC was indicating that a number of the beneficiaries were really struggling and consequently they thought that a regular payments system which is reviewable should be put into place. We considered a paper looking at actually who did we think was going to benefit from this, and it obviously had to be those on the lowest income where their income and expenditure was understood and that we would as far as possible, start to institute a regular payment system. We were very concerned that the level at which we might be able to support people would be much lower than we actually wished to in the first place, but in looking at the resource available and I still am convinced given the number of people we think this might benefit, that we are going to be heading for a fair overspend at the end of the day which will cause big problems and we've got to discuss with the Department what happens in that case but nevertheless, we are still in principle wishing to establish a regular payment system which is reviewable. We have been very mindful of the dangers of raising expectations if we suddenly find we are utterly inundated and the census that we will have to undertake means that we've identified more people than we anticipated, but nevertheless, the board is still intent on trying to take a step forward to alleviate the financial situation of its most disadvantaged beneficiaries."

**GRO-A** "Could I suggest that if you want to make a regular payment, why don't you start with the carers, make them a 'one off payment' yearly so that they can, when they can, take a holiday, have a pamper day if you want to, go to the cinema if they want to, and the money is already there. You could do that once a year." AL: "A carer's payment." JB: "But can I just say, that would be different, if the aim of the regular payment system....." AL: "Nevertheless that is a different issue but we will take that up". **GRO-A** "I brought this at the very first meeting last year." AL: "I know you did." JB: "But the idea with the regular payment scheme was to help those on the lowest incomes and one of the things that had come out of the work with the NWC was the fact that so many people had come through the committee asking for support on low incomes...." **GRO-A** "What do you class low income; do you class it on state benefit level or do you class it on something else?" JB: "Well there are people that we know that are living below the formal definition of poverty line for example; we see that kind of, that's what I mean." **GRO-A** "Yes but is that state benefit or working ....". JB: "People who are working are unlikely to be below the poverty line." **GRO-A** "Not necessarily". JB: "Not necessarily but I said 'unlikely', the majority of the people that we see at that level are those people who can't work who are on benefits, maybe on state pensions only or something like that". **GRO-A** "What about if you're on state pension and pension credit guarantee, which like income support is a top up." JB: "It would depend, what I'm saying to you **GRO-A** is there are a number of people on very, very low incomes..." **GRO-A** "I know, and I'm one of them." JB: "And that's when all those different things are added together, and some people actually don't have that many things that add to that..." **GRO-A** "I understand all that..." JB: "so those were the people that we were specifically trying to assist. Now when we made the business case to the Department of Health, there is this thing called '60% median

income' which is basically 60% of what the average income is, essentially, and that is the definition of the poverty line." [GRO-A] "there's a number of different definitions on that..." JB: "It changes 'year on year', it's assessed by the Government's statisticians each year but that figure is 'kind of published'. Now, we felt that 60% median income which is the poverty line was not something we wanted to aspire to, we wanted to aspire to getting people above that and so we did various models to look at costs and when we put the business case to the Department, we put the business case on the back of 80% median incomes so that was lifting people above that poverty line and that would have cost us an extra £3 1/2 million pounds and that is what the Department of Health didn't want to give us essentially." [GRO-A] "So it's an extra £3.5 million per annum?" JB: "yes, that's what that 80% median income level would have been and what we'd wanted to do at that stage was to make people up to that level so if the 80% median income for a single person was £11,000 for example, if you were only on £6,000, we'd look to make up the difference between £6,000 and £11,000 and that is what in total based on the modelling that we could do would have cost us 3 1/2" and that's what the Department threw out." [GRO-A] "Is this treating an individual as an individual's income or are you talking about household?" JB: "It's household income, but it depends on the household composition so these 60% and 80% median income levels change according to whether you're single, whether you have a partner, whether you have children..." LC: "Just like a standard definition that is used?" JB: "Obviously the greater the number of people in the household, the higher the level because if there is one of you, or if there is two of you, you need more to live on than if there is one of you. So that was what the department didn't want to fund, but as Ann said, the board was still very keen to try and assist those people that we knew were living on those low incomes but because the department didn't want to give us that extra money, we were basically left this year with a situation where any system we could implement had to come in around the £800,000 mark, so that is a quarter, less than a quarter, of what we would have needed to run that system that we were hoping to do so what we've looked at, at the moment is having to go back to the 60% line so that's effectively the poverty line (and there are still plenty of people living below that), but again because we don't have all the money we wanted, we won't be in a position to make people up to that, all we will be able to do is make some additional payment to those households that have fallen below that level; we won't be able to make it up. At the moment, we don't know exactly what kind of payment we're gonna be able to make so the next steps is that at the end of August/the beginning of September, we are going to be writing to everyone setting out what we are hoping to do and setting out what those 60% median income levels are for those different households so people know what the income levels are and then asking people who want to be considered and who believe that they would fall into that income bracket to complete a census so that we can then model how many people we've actually got and then work out what level of payment we can afford to make from that £800,000 that we've got available. So it's significantly less than we would have been able to do if the Department had supported our business case but as Ann said, the board's very keen to do something because we are so mindful that there an awful lot of people living on very low incomes and at the current time, that is the best that we can do to help those people and obviously if we were to move up the level of income that are trying to assist the greater the number of people that would qualify and therefore the amount that we could give them would go down, so we are having to do this very much based on absolute income and real financial hardship so it's not going to be a scheme that benefits everyone because we are really trying to target

those people who are really struggling financially.” <sup>GRO-A</sup> “Obviously it’s a bit disappointing it’s not going to be able to achieve what everybody wants, but I do think it’s important that you’ve kept yourselves mindful of it and you’re going to introduce something, even if it takes you to an overspend because that will test the Department’s so called commitment where they keep saying ‘you’ve never spent up and therefore they’ve never needed to consider you needed more money’..” AL: “Well yeah, an uplift thank goodness, but nevertheless we’re just trying to be very, we were trying to protect the grants schemes so that even if you get a regular payment, it doesn’t preclude that; we were trying to protect other benefits and payments that we make; we could try to keep the staff costs down because this is coming from the general allocation to try our very best with a margin of risk (big margin of risk) to make this as satisfactory a scheme as is possible.” <sup>GRO-A</sup> “I do think it’s important to be seen (it might be risky), but it is important to be seen to be using all of your resources.” AL & JB: “Absolutely.” GW: “because you haven’t been in previous years have you? You haven’t used all your resources that you’ve had.” AL: “Well we haven’t been able to locate sufficient, you know if you’ve got a level of, of...we think that, well we believe, when we’ve asked the Department, that they, they’ve made a guestimate of how many people might come forward and despite your publicity and ours, we’ve never been able to reach that level which has been of concern to us, which is why we’ve had to rethink how do we use the resource that’s available, absolutely get it on the nail, and I have to say I think it will probably go up”. GW: “From those costings you would have included the income of the carer, or the wife or the partner?” JB: “Yes, because it’s household income.” AL: “That’s how it is.” GW: “We have a big problem with that you see because basically what you’ve got then (I appreciate your situation) but what you’ve got then is a situation where the carer or the wife, or the husband (if it’s the lady that’s infected) is actually subsidising the ill-health potentially of the infected primary beneficiary, I find that shocking that the wife’s and partners and husbands etc, have to basically ‘bale out’ the Department of Health.” JB: “That’s kind of a separate issue really isn’t it, that’s kind of part of your bigger arguments with the Department of Health.” GW: “It sort of ties in with your using it within your modelling.” AL: “We did discuss all of that, I mean this has taken a long time to think through because, you know, we’d started out trying to be absolutely as generous and reasonable as possible but we think that, you know, let us do the census and let us recast generously.” GW: “I think this just shows what our health, this is what we’ve been up against for an awful long time.” JB: “I think just sort of coming back to this Glenn, one of the things we also really wanted to do was whatever kind of income benchmark we set, it had to be something that wasn’t kind of made up and it had to be something that was kind of, if you like, nationally/internationally recognised so that there was some justification for where we have drawn that line and sort of based on some other experiences elsewhere, using this kind of model whether people have kind of views about household composition and everything else, it is a genuine external ratified benchmark that we can use and so that’s why we were really keen to do that as I said you know, we wanted to go beyond that and was actually aspiring to get people up to the poverty line is not the kind of aspiration that we want more than that, but our hands were tied financially as I said, what we’ve got to play with is less than 25% of what we needed to do the system we wanted. But I think once we’ve done the census and we’ve got all that information about people’s incomes, it will actually give us some extra information to possibly go back to the Department of Health with an embellished business case next year, say ok, we still need this £3.5 million, now can we have it please? So it may be that certain

things will change, we don't know what's going to happen in terms of final settlement, it may be that, you know, where the APPG enquiry and the Alistair Burt work end up, is that the charities need more money (I know that's not your ideal outcome, you want us gone), but if there were more pressure/evidence put on the table which a settlement for the whole community might entail, then this might be something they would settle for doing and so we'd be able to revisit this, so I think it kind of takes us a bit further forward, its not where we want it to be, but at least we are still in a position to try and help those who are in greatest need. [GRO-A] "Coming back to carers, I could go out to work but my husband's circumstances won't allow it, I could be earning a living, I could have been for years, instead I have to get £61.35 per week, out of which I've got to clothe myself, anything I need if I want a night out, you try going out (I mean I had my nails done a couple of weeks ago, that was a gift) I have to rely on friends, I can't afford it on my income. I have to put into the household on £61.00 a week, what am I left with? I can't come to the Caxton because by the time I've come to the Caxton, I can't give you the estimates you want, I can't give you the information you want, so we're back again to the same thing, but then again, you are going to take my £61.00 a week back into consideration with my husband's pension. I'm disregarded again, I'm not an individual." CL: "Just bear in mind, when you're looking at the sort of figure we are working to on the policy figure, it increases if there's two people in the household, or if there's two people in the household with children, so it does reflect that." [GRO-A] "I do understand that, but as a carer who is getting £61.00 a week when I should have been making my own way in life, and then I have to come and say 'well, I'll wait 6 weeks, 8 weeks while the Caxton make their mind up whether or not I can have a pamper day, do you think that's right? Because I don't, I can't just say 'oh, I'll go for a meal tonight'. I have to save up weeks to go out for one night. I have had one night out this year and that was a fortnight ago. How many night's out have you had? And how many night's out have you had? I've never been to the Theatre, never, because I can never afford it. The last time I went to the pictures was in 1990, because I can't afford it. If I want a new pair of shoes, I have to save up for them, I can't afford it. I don't have any debt, because I can't afford it, so what is the Caxton going to do for me? What is Caxton going to do for people in my position? In three years, they have done nothing; we have said this last year at the very first Partnership Group meeting, nothing, nothing has been done. It's still exactly the same, what is the point?" AL: "Well I shall be reporting this back to the board on Thursday and I will ask that the NWC consider your suggestion of a 'one off payment for carers'." [GRO-A] "But I suggested this 12 months ago at the very, very first Partnership Group meeting". AL: "Yes, I know". [GRO-A] "When I was convinced by Mr Lister to reclaim and then I put in for my funeral plan and low and behold 'we can't give to carer's because if we give to carer's we have to give to everybody else'. My income has been limited as much as my husband's, my husband can have a funeral plan because he's stage 2, I can't, but where am I going to get insurance? Are you going to leave my son to bury me, because he can't afford it, I can't afford, and I can't afford to save. So if, if my husband dies before me – that's fine, his funeral's paid for, if I die after my husband, who pay's for my funeral? My son who can't afford it? Because he can't claim from Caxton". JB: "Yes, your son would be able to apply to us for a funeral cost for you." [GRO-A] "Well, can I have that in writing?" JB: "It's on the website." AL: "I think that the whole issue of carer's needs discussing, I think that would be extremely helpful." [GRO-A] "But it's not just me that's in this position." AL: "No, we know that." [GRO-A] "it's all the other carer's." AL: "Yes, I'm not talking about you as an individual; I'm

talking about carers, the whole issue of carers.” [GRO-A] “It’s no good saying ‘oh well, we’ll discuss it on Thursday and 12 months down the line things are still the same. We can’t carry on like this, we haven’t got time, we are looking after people who are ill.” AL: “Yes, I understand that, ok, thank you.” GW: “There’s another one actually that’s just cropped with you saying about the funeral plan [GRO-A], and that’s the recent minutes that have been put on the Caxton website and it confirms that the funeral plans are only allowed for stage 2 infected beneficiaries, why only stage 2’s? Why not the stage 1’s as well?” JB: “Because the..I think it’s fair to say that people at stage 2.....” [GRO-A] “Are more likely to die basically”. JB: “Well its, I think on the whole (I wasn’t going to say that [GRO-A], but for people at stage 2, tend to be more imminently worried about that as an issue, if we, we actually did a calculation about how much it would cost for us to provide everyone who was registered with a funeral plan, it would be more than our annual allocation, so if we gave everyone a funeral plan upfront, a year (well we’d only obviously have to do it once) but if we decided that we could do that and once we do it for one person, we couldn’t not do it for someone else, that would cost more than our annual allocation, so one year’s an entire funding plus, plus, would be wiped out on funeral plans and one of the principles we try to operate by is that we try to do, make our decisions in a way that we could do the same for anyone who came forward in a similar situation. So if you, if someone who wasn’t at stage 2 got a funeral plan, they’d be, we would have no justification for turning down everyone else that came forward and that would mean that we couldn’t do anything else that year and so we have to make those decisions based on what our funding is and we could go back to the old argument about, well, we don’t like this charity, we don’t like the way it’s funded and everything else, but we have to operate within that pot, and that is the reason that there are certain limits put on things because if we didn’t do that, we might, you know some grant making organisations run quarterly grant programmes and if they run out of money at the end of the first quarter, they go ‘sorry, we’ve got no more money left’. We would not want to be in that situation, we would not want to use up all of our money in the first quarter of the year, so we have to put some of those limits in, in order to make sure that we’re going to be in a position to provide someone who has that same need with the same support whether they come to us in May or whether they come to us in January the following year.”

[GRO-A] “How do you assess the impact on your budget if you were to take out a kind of a filter along the lines of that what Skipton uses where they use these scientific documents that have shown when people should become more imminently concerned about their health as they are getting older as well, with relation to liver disease in which case it was something along the lines of ‘25 – 30 years infection’ and you can really start to get concerned about your health at that point, well that may not apply to everyone, but you could use that as a threshold for saying people are entitled to claim for a funeral plan.” JB: “I suppose the thing is, on the Caxton side, we don’t have/do those medical assessments so we don’t have access to the Skipton data, but we would have to kind of revisit when people were infected; as you know, Skipton makes all the assessments of the number of tests to assess where and how far people have progressed. We are not in a position to do that. [GRO-A] “There is information in the public domain and that applies across the board to everyone that’s registered with Caxton, it’s a very simple mechanism you could use, and the actual date of infection would be very easy to, you could ask for that on the application for the funeral plan.” [GRO-A] “Yeah, but saying that [GRO-A] not everybody has a date of the infection.” AL:



“That’s true.” [GRO-A] “No, but it’s usually accepted (especially within the Haemophilia population) that it was the date of your first infusion and for most that’s usually childhood. JB: “But we would have to then be looking at medical records and everything else and we don’t have the clinicians to do that, so this is kind of, essentially, what I am trying to do is explain the stage, why we’ve come to that decision about funeral plans for stage 2, but that principle about trying to do the same for everyone, so that if someone comes to us asking for a specific in May, someone coming to us in February is going to get the same answer, that is about actually going, ‘well if we modelled this, what would it cost if we did that for everyone?’ And we just simply can’t and that was the case, but I think it came out at over £3million, wasn’t it when we look at it and that kind of set up blows all our budget for the year, that’s not a sensible way to support people because someone who may be is only 35 is not going to, you know they’re going to have other things that they want support on, someone who is 50 might have other things they want support on, as opposed to blowing all that money in one year on funeral plans.” [GRO-A] “Perhaps this is something you can build into your future business plans because you’ve got a mechanism by which you could extend this scheme and still show that you are, you’re being mindful not to just give it ‘wily nily’. JB: “But I think there’s also the issue, you know we’re looking at charitable need as well, and can someone say who’s 35 demonstrate that they have charitable need for a funeral plan at that point, when we try and explain it, some of it gets a little bit over simplified....” AL: “What people need is reassurance about what the rules are. Reassurance if this happens, what can I then do?” [GRO-A] “And recognition, because funeral plans as we’ve heard are not available necessarily if you’ve got these kind of life limiting medical conditions so you do need recognition that is an issue for people in the infected community.” AL: “Yes”. JB: “But to be fair [GRO-A] if someone came to us who had a diagnosis of something else, occasionally it happens where you know, they’ve effectively been given a certain time to live and it might not be stage 2 related, then the committee would look at that as an exception. AL: “But I think the community needs to know that.” [GRO-A] “Could you not stagger the funeral plan, say so many stage 2 per year, so many stage 1 per year, so many carer’s per year and do it over say 5 or 6 year’s rather than all at once?”. JB: “Although I think given what we are looking at doing with the regular payments system I don’t think we would have the funding to do that.” AL: “Within our allocation we certainly can consider it.” [GRO-A] “Can we not make a payment upon death? You know, you are going to get roughly an idea of the number of deaths from stage 2, we don’t know about stage 1 because, you know they’re dying at a far greater, I’m right in saying this aren’t I? That stage 1’s are dying at a far more regular than stage 2.” GW: “Page 41 of the review shows that stage 1’s are dying in greater numbers than stage 2’s for some reason.” JB: “But is that in numbers or percentages? GW: “What’s your experience of the death rate within Caxton?” [GRO-A] “You don’t have the complete figures I bet.” JB: “No,.. no”. AL: “But certainly that’s a helpful suggestion.” [GRO-A] “There is a grant as you know with the Mac Trust am I right? There was a payment upon death.” JB: “But we would do that as well, so that’s what we’re saying....” AL: “I think we just need to be very clear about what it is we’re doing, what the rules are, everybody should know and its just that....”

## Communications

Victoria Prouse (VP): “Firstly, we sent out a survey to primary beneficiaries and widows and carers earlier this year, June time, and the idea of the survey was to get an

idea from people want forms/types of communications they would be interested in receiving from us i.e. newsletters or having meetings and then also to say if we are, what is it you want to hear from us? So what's the kind of things you want to find out from us, going back to some of the stuff we were discussing earlier to do with what information would be useful, so that we're not doing something that people don't want to know. So, we've had a brilliant response, we've had about (as the figures from yesterday) about 61% of people we wrote to responded which is great, obviously responses are still coming in and as they're coming in we are adding the figures to the spreadsheet. The two sort of key things, certainly in terms of the types of communications that people were interested in, the sort of the overwhelming interest was in some kind of newsletter, be that by email or by post, I think there's probably very few people who didn't want, express an interest in one or the other of those two so that's been a really resounding interest, about 60% coming back who are interested in that. We've also had some interest in the website being updated as we've discussed previously and keeping information up on the website. I think it's been quite good to point out that we've obviously had quite a lot of people who are very keen that we didn't just do everything online, that we still have paper versions of things and that we still use post where applicable, and they still wanted that contact with Head office and the phones, and that side of things." [GRO-A] "Is it clear how many people would go for the website side of things that obviously then would have access? Is it clear how much percentage of the people responded are interested in the website side of things, so you obviously know they've got website access." VP: "Just under 50% actually who are interested, and likewise in terms of the newsletter the interest in the newsletter we got 60%." JB: "Some people said they'd be interested in either, but effectively there was a kind an even split between people who would want it by email and people who would want it by post." [GRO-A] "At least that shows at least 50% have got access to email and so on." VP: "Yes, we do get quite a lot of...." JB: "Well, that's 50% of the people that replied obviously, not 50% of the total community, and possibly the people that didn't reply, will potentially more likely to be those who are more reliant on paper."

VP: "The other option we gave people was that to having regional meetings, there was a much lower response rate from that, about 16% of people across the whole community were interested in having regional meetings, around about 90 people in total who came back with an interest in regional meetings." AL: "But they'd also ticked everything else" VP: "Yes, they'd expressed an interest in some other things, so one of their options rather than their only option. In terms of the type of information received, we gave people four options which was more information about Caxton, the stuff we've talked about the processes and grants available, news from the office – that kind of thing, information on new treatments for Hepatitis C, information on benefits out there that's available and also some information or signpost information about other organisations that might be of interest to people. Pretty much across the board there is general interest in all of those areas, out of all of them the lowest was the information about new treatments, there was slightly less interest in that – possibly because this was a mixture of primary beneficiaries and widows and that there wouldn't be an interest in.....Otherwise, a pretty even spread across the rest, there was a really strong interest in all three areas and then some of the other things we obviously asked people in another box for people to suggest other areas of things they would like to hear from. Some of the more popular ones, we had a few people asking about stuff more specific to older people rather than sort of the working

age, I think particularly that came from the widows. Some information more on medical to do with cancer treatment and kidney failures, so other conditions that weren't specific to Hepatitis C." [GRO-A] "But other conditions are specific to Hepatitis C, it is not just liver cancer." GW: "It's worth remembering that." JB: "No, but I think Victoria just meant there wasn't information about Hepatitis C, it was about related conditions which weren't Hepatitis C as whereas people are interested in that information and new treatments." [GRO-A] "Yes, but related conditions can be caused by Hepatitis C". VP: "So in terms of what we do, obviously this has all happened in the last few weeks, we're still getting the results in, they're dribbling in. Most of them came in within the time period, but as they come in we are still updating, and obviously the board will be discussing this on Thursday when they meet, because they haven't had chance to discuss this yet. Obviously we will be updating the website to reflect some of this, some of the things that people have asked for, the updates and we've got some information we are just preparing to go on the website to reflect some of the requests people have asked for. We are also going to be recommending to the board on Thursday that we look to apply it to the newsletter as that was the overwhelming feedback that we've had from people, and that we will be offering that in the post as a hard copy as well an email version and then the board will then discuss what we do whether we proceed with regional meetings because it's quite a low interest in the first place and the trouble with meetings is that once you then arrange a date and time, less people can make it, so once you've got that, it's going to be even smaller interest in that possibly for people that can actually attend at a given time."

[GRO-A] "Can I make a number of observations; on the communications exercise, a couple of criticisms really, you've asked them about their interest in the regional meetings, but I think you could have expanded that to ask on their interest in how they wanted to be represented further, so are they interested in this kind of Partnership Group representation or are they happy for people to be represented by 'your so called campaign groups, or representative groups? I think you've missed an opportunity there." AL: "This is the first of many" [GRO-A] "The other thing, you didn't include a question on feedback. This was all about how they wanted to receive information from you; what about them providing information back to you..." JB: "That's something that's planned for later in the year, so this was just about information coming out from us." AL: "The feedback loop, what I've asked Victoria (as she's now taken up her post) to do, is to put whether everything is alright, what were the handicaps, so we get a continuous feedback loop which can be fed to the NWC and the board, so that's 'in train'." GW: "You could have also expanded into educational advice in there, not just meetings; similar to what the MFT had, because I know they found it useful. We held a demonstration in David Cameron's constituency earlier this year, we stayed over the night before and met with a number of people we've never met before and those 2 or 3 hours actually chatting to people who were in the same or similar circumstances, was invaluable and people really did appreciate it. If there is only 16% of people that would like to do something like that. There will be a cost element to Caxton, I do think it would be something worth considering and you could expand it into other things, as I said, the educational and advice seminars in terms of health related issues, benefits, living with hepatitis C etc, etc, it could be really useful." AL: "I think that Glenn, I would agree with you about education and advice and I think it was in that context that we suggested such a meeting in the first place." JB: "I think the questionnaire did actually ask those things." GW:

“Educational and advice? I don’t think it did.” JB: “I don’t think it used exactly those words but it talked about, it said an opportunity to meet members of the Board and then a number of other things which was about what you’ve just said.” GW: “I don’t remember that.” GRO-A: “I don’t either.” AL: “Anyway, this is round one, we will now be going back out to people, not just via the newsletter which we will pilot, but to answer GRO-A’s questions about representation and to really push the issue of education and advice, how do they want to receive it and do they want ‘this, that and the other?’” GW: “It’s absolutely essential really, because this community are so insular, the amount of people we have contacting us, who are desperately private and don’t want information putting out, so they feel (even sometimes within their own families) that they don’t have the opportunity to speak with people to express their concerns and their worries and their fears, absolutely invaluable opportunity to meet with other people who have been through exactly the same things.” JB: “What was interesting though, which certainly surprised me on the survey responses we got back where a lot of people who were very emphatic that the last thing they wanted to do was meet with people who are in a similar situation to themselves and that was quite interesting and that might reflect actually why the take up of that is so low, because people, you know, they kind of don’t want it to be a big issue in their lives and they just want to get on with it and the last thing they want to do is mix with other people who have been infected with Hepatitis C, and I was quite surprised by that.” GW: “I think that’s a relevant point, and I think a lot of people in our community are of that mindset, they don’t want it to impact on their life in anyway, they want to carry on doing the normal things; I was certainly in that position, you shun everything, you don’t want anything to impact with your employment, with your hopes and ambitions, with your relationships, you just want to ‘bury your head’ basically and its not until you’re put in a position where you can’t ignore it any more, that you get to a position where it actually controls you and you’re not controlling it, and I do think it would be useful to have these for those that want to.” AL: “I think it’s a fundamental responsibility really, of ours is to provide a source by which education and advice can be provided and there are different ways of doing that, some are very confidential and very helpful like some of the helplines that have operated in the past in other organisations that have been very heavily used in just such very difficult circumstances, so we’ve got to think of the best way of doing that, that will suit the needs of the community.”

GRO-A: “I think you might even see a split between the type of beneficiary as in the haemophilia population versus the none bleeding disorder because bleeding disorders tend to take a great interest in their treatment and they would want to know how others are getting on with the latest medication that they are trying with Hep C at the moment for instance, whereas others tend to ‘not have been stung as we were’ and therefore are still very much guided by their consultant and the NHS advice.” JB: “I think what’s quite interesting is there was a very big interest in hearing about other organisations and one of the reasons that we kind of changed the role that we had in the office when we appointed Victoria, was to focus on, again coming back to this issue of money, you know, we’re never going be in a position to employ our own benefits advisor, housing advisor’s, advisor’s on issues relating to older people, those kind of things, what we want to do, is to have those links with those other organisations so that we can refer people on and interestingly again, some of the things that came out of the survey, was a lot of people saying, you know, when they ticked the ‘other organisations’, other information they wanted, was specifically about

things like older people, and I know there's been, you know, several people that Victoria has already been able to refer onto other organisations as a result of what came out of that, so I think over time, its about building up that bigger network so that when people have issues which we don't specifically have the 'in-house' kind of expertise to assist with, we're in a position to at least signpost people on and we have that relationship to be able to do that, so that's hopefully going to be, you know that would be a really positive development." [GRO-A] "On that issue alone, why don't you suggest, rather than 'mini meetings' that you do maybe two weekends for beneficiaries to go and meet up, not for any (how shall we put it) meetings where a lot of people won't go to meetings, but they might to go to a family weekend. In the haemophilia community alone, you have got such a wealth of knowledge on housing, benefits, you name it, there's somebody that has been in that position and have information that they could pass on. You will find that a lot beneficiaries will talk to another beneficiary were they won't talk to you, so if you were to use, say a weekend..." [GRO-A] "You could either do it through general 'chit chat's' and dissemination about that, but you could potentially also have a 'breakout' group, where people can chose whether to try it or not." [GRO-A] "Exactly, but most people would sooner have a weekend like that rather than (how can I put it) official." [GRO-A] "Well, it used to work very well with the Macfarlane Trust when they did those things." [GRO-A] "Yeah, but we've never had that on the Hep C community." [GRO-A] "But again, that's come down to funding and I think one of the issues with the Macfarlane one was that they were very, very expensive and only a very tiny proportion of the beneficiary community could actually get any benefit from and it was the same people attending time and time again." [GRO-A] "It was actually a little bit to do with that kind of overcoming the barriers, I know even from my own prospective it took me many years to kind of decide to go and become involved because you're so private about the whole thing." [GRO-A] "Exactly, and you don't realise that people are in the same position as you." [GRO-A] "Once I'd actually broken the ice and done it, I was like 'why have I waited so long' it was actually so positive." AL: "Certainly it's a valuable suggestion, thank you and we will look into it, because this will have to go back to the board."

#### Partnership Group

JB: "We were asked by the board to review where we'd got to with the group since we'd started around this time last year (you've all had a short paper with the pack). As you know we started off with this group largely being made up of members of the campaign groups involved. As the beneficiary community has grown in the last year as well, we wanted to go back and look at what the makeup of that community was because we felt that the Partnership group really needed to be representative of the beneficiary community and all the kind of sub-groups that it's made up of, and clearly as we've been talking about earlier, we have all the primary beneficiaries but we have widows, we also have people who are the dependents and carers of those infected, we have a range of people in terms of age group, we have a range in terms of those who have haemophilia and those who don't, there's obviously male and female split as well, and so when we looked at all of those and bits of information, we decided that a year on, now was probably the time to try and get that broader representation on the group and so that is why we are wanting to expand it and the numbers that we're suggesting are literally to try and reflect in a proportional way, the types of beneficiaries that we have, so primary beneficiaries are obviously the predominant group, we have male and female, we have people with and without haemophilia. The

next highest group is the widows and widowers as well of course, we have male members of the bereaved community and specifically carers as well, and in order to make the group (if you like) a workable size, looking to need to shrink down the number of people who are involved from the campaign groups and I think we omitted to put it here, but in terms of the 3 campaign groups, we know that what we are proposing would mean that your representation would kind of go down by one from each of the groups for this expanded membership, but we would obviously be happy for a different person from the campaign groups to come each time, so it would mean that if someone wasn't able to come, they would be able to send a deputy so that they didn't lose that representation each time, but that's essentially what we are trying to do. At the moment, in terms of the other stakeholders; the Chief Executive of the Hepatitis C Trust has always been invited, he's unfortunately never been able to attend and I know from the earlier discussions, not everyone would welcome someone from that group, I think people with Haemophilia had sort of some slightly different views from the whole blood ..."<sup>[GRO-A]</sup> "Do you take any views from the Hep C Trust on board? How do they represent views?" JB: "We have kind of infrequent contact with them, we have kind of more contact at an operational level to be honest than we do at board level" AL: "Yes, the helpline manager is usually the person we do contact." LC: "Should it be then a representative from the Hep C Trust?" AL: "That's what we've asked for." LC: "If there is someone who is helpful who understands the issues everybody might face maybe..." GW: "We would welcome somebody from the Hep C Trust and I've asked Charles Gore every time now, but he's not been able to make it. I contacted him again before this meeting..."<sup>[GRO-A]</sup> "But then we only get short notice of the meetings. I mean this meeting was supposed to have taken place in May, I phoned in April to ask when it was going to be and was told nothing had been organised. Then I was told June, then I was told it might be July, then it was August." JB: "But coming back to Charles Gore, it hasn't mattered how much notice there's been of the meeting, he hasn't been able to attend so we were talking earlier about we would encourage him to send a deputy." GW: "I did ask him that actually." AL: "Because his 'helpline manager' is really, really useful and has a wide range of understanding."<sup>[GRO-A]</sup> "Did he come to the original meeting?" JB: "No, he's never come. I think we've always had the Chief Executive or the Interim from the Haemophilia Society and we were approached by Haemophilia Scotland to also be involved if they could." LC: "Dan's just been made Chief Exec there, I think they would be a positive thing for the community." AL: "Yes. Is there a similar group in Wales do you know?" LC: "No, we cover the whole of the UK still so we cover England, Scotland, Northern Ireland and Wales, but Dan and Haemophilia Scotland are specifically looking at issues in Scotland, a lot of it is around campaigning amongst other stuff, so we cover the rest of the UK."<sup>[GRO-A]</sup> "We also have a Scottish and Welsh rep as well (Taintedblood) so we get feedback from them." AL: "In talking to the Welsh Minister, he's asked me to see their equivalent of the APPG which is I think Chaired by Julie Morgan, Rhodri Morgan's wife whose now got his seat, so I have arranged to do that."<sup>[GRO-A]</sup> "They've got big problems in Wales." AL: "Yes, I know." JB: "What we are proposing to do now is, obviously there will be some discussion now, but the next steps would be to actually to go out to people specifically asking them to express an interest. You may remember that we approached the bereaved community last year to get a representative to come on we do actually have someone, her name is noted in the last minutes,<sup>[GRO-A]</sup> who has agreed to be the representative for the bereaved community, so she was unfortunately not able to come this time, but we've kind of, you know, we were incrementally starting to do it, but I

think we need to, it would be nice to get a male member of the bereaved community as well to reflect the people that we support. But to actually now write out to people and see who'd be interested and take it from there, because clearly based on the communications survey, not everyone is going to be." [GRO-A] "How will I go on because as a member of the Manor House Group I was also supposed to be 'for carers'." JB: "I think we would need to talk about that and work out what, in terms of the Manor House Group, what your representation would be." [GRO-A] "But I'm a carer as well as campaigner." JB: "Yes, I appreciate that. But I mean, Glenn is here as a primary beneficiary as well as a campaigner." [GRO-A] "There are a couple of points I've got on that. The question mark over how you are defining a campaigner, because we've got 700/nearly 800 members, do you count them as campaigners just because they send to us their issues? The Haemophilia Society, they make representations through the APPG." [GRO-A] "My husband who is a haemophiliac read this, and he turned round and he said 'to me that is insulting and discrimination to you, but also reading that, every single haemophiliac and their partner who have been infected with Hep C, at one time and other have been a campaigner.'" JB: "What we mean by that [GRO-A] is that there are people who are very actively associated with those groups and who would want to come and represent those groups in the way..." [GRO-A] "If you are going to make this definition tighter, are you basically talking about the board members of CBC, TB, and Manor House?" LC: "was it 'acting with that hat on'?" JB: "Yes, exactly." LC: "So you are coming as a representative of that group?" [GRO-A] "I have never done that, I have only ever come here to be a representative as a carer." LC "It sounds like you could be here as a carer and your role here would be as a carer, you might happen to be a part of a campaign group and that's fine, or you might be here as a representative of a campaign group....." AL: "We just need to tighten the definition, that would be helpful". [GRO-A] "The other thing was, on the primary beneficiaries you've got at least one with haemophilia, at least 50/50, I think there is the potential there for von willebrand and haemophilia representation and you then get male and female." LC "It could be from the bleeding disorder community, which is more representative." AL: "Well this is just a suggestion at the moment to take back." JB: "That's a fair point because that would then would do the male/female balance."

[GRO-A] "Also, I have a question, it might sound silly. What is the role of the Partnership Group?" JB: "I think what we'd need to do is ..." [GRO-A] "No, what is the role NOW of the Partnership Group, and what has the role been, because I am very confused because, I will tell you for why; I have been a member of the Partnership Group since it started, I have never once had a telephone call, an email, any letter, anything to say; this is what we're thinking of, what's the feedback from yourself, from the carer's position (I don't know about any of the others) we have never had a feedback, we have never had a phone call, we've never had a letter, we have never been consulted, you've gone off, you've done everything and then you've come back and said 'there you are, that's what we're going to do'; so why have the Partnership Group?" GW: "I have to agree with that, I mean this is actually 'a case in point' regarding the changing of the PG Group." [GRO-A] "It's not even about that Glenn, I mean when you come to this paper, we've decided; the board's decided; this one's decided; that one's decided. Everybody's been included at the Caxton, not once have any member (as far as I'm aware) of the other side of the Partnership Group been consulted. How can you call that a Partnership when the Caxton board are making all the decisions, there is no consultation, there is no information, there's nothing given to the other side." JB: "I think that's a little unfair actually, because we talked about the Regular payment

system last time, we've got your input, we've now talked through this time what we're proposing to do on that, and we've talked through the stuff on the communications and about the regional meetings." [GRO-A] "There is no communication between this side of the table and that side, in between meetings. It was last November I think that the last meeting was. Have you spoken to [GRO-A] Glenn? Myself? [GRO-A] The Haemophilia Society? About any of your thoughts on this or anybody from the Caxton? Have you spoken to any of us? No, nobody has. I had to phone (I don't know about the others), but I had to phone in April to find out what was happening about the May meeting which is now obviously August, nobody phoned me back, I had to then phone again and phone again, and phone again. I even had to phone up and ask when the minutes of the meeting were being sent out." AL: "I believe that's my fault [GRO-A] and one of the things I've been talking to Charles about, is about improving the communication, or setting up the communication between..." [GRO-A] "Because there isn't any." AL: "That's not exactly right, but I fully accept the responsibility for absence of adequate communication with the Partnership Group and have been discussing with Charles how we do improve that and to make it more meaningful. We have brought the Partnership Group paper (which you have seen at the same time as me) to this meeting to ensure that we do get your views back and we certainly talked about the regular payment system with you before it went, which was important." [GRO-A] "You're missing the point Ann, its not about the regular payment system, it's the contact in between." AL: "I understand that." [GRO-A] "There's nothing." AL: "I understand that and I apologise for that, and I will rectify it." [GRO-A] "Because it's 'them and us'". AL: "Well that's not how it's supposed to be". [GRO-A] "That's basically what it is' them and us'." AL: "I don't think so." GW: "I have to agree, and then we have an ongoing trawl and fight to get things changed. The fact that the word 'beneficiary' was changed to 'client', and then we had an ongoing fight for months and months to get it changed back to 'beneficiary' again. You know, if you'd have spoken with us beforehand and got our views and opinion, then we would have never gone down that road, and this is just another case in point. At the first PG meeting, we discussed the make up of the Partnership Group. I wanted the same sort of input that the MFT people had; with the MFT all of the beneficiaries can attend their meetings and rightly so." [GRO-A] "Not any more." GW: "because each individual's want to give their input. At least have the opportunity. I know a lot of them won't want to, but we should at least have the opportunity of attending and speaking on their own behalf because a lot of people don't want campaign groups speaking on their behalf." AL: "That's true." GW: "So, it was arranged that we were going to have 2 meetings a year with the campaign group members, and we was going to have one overall meeting every year that everybody could attend, and then we read things like 'now the board has decided' and you think well, where did that come from? We haven't been consulted at all." [GRO-A] "As far as we're concerned it was agreed." GW: "I think [GRO-A]'s question's right, what is the role of this Partnership Group?" AL: "The beneficiaries are saying that's not what they wanted." [GRO-A] "Yes, but this was agreed before you even sent the questionnaire out." AL: "You were talking on behalf of the campaign groups, now we were testing it with the beneficiaries and that's only right and proper that we do that." [GRO-A] "I understand that, but at the last Partnership Group meeting we assumed (rightly or wrongly) that we had agreed that the next meeting was going to be in May." AL: "Yes, I understand that." [GRO-A] "And we had agreed that there was going to be, later on in the year or, no in May actually, the same time, because of the daylight and it was of the weather that you were going to hold one big meeting for all beneficiaries. We assumed that had been agreed, and then all



of a sudden, there is no Partnership Group meeting, there's no big meeting, it was cancelled, nobody bothered to tell us." AL: "I apologise for that." [GRO-A] "I think that's where these action points come in, the things that we've agreed and the things that have got to be addressed." AL: "I agree." JB: "I think it's also about being clearer about the other bits of the jigsaw that we have to take in terms of, even the regional meetings, I mean we, there's obviously a very low uptake on that from this survey, and sometimes it might be agreed that, that is what might happen, but actually if there is no interest in doing it, then it can't go ahead." [GRO-A] "Obviously, then consult with the Partnership Group." JB: "That's kind of what we are doing today, we've got the results of the survey and you need to understand we are sharing the results of that survey with you before we've even shared them with the board." [GRO-A] "I do understand that." [GRO-A] "I've got to say, it's more than the Macfarlane Trust ever did with their communication survey." [GRO-A] "But there was one question you actually left out of the communication survey. What do you think of the work that the Caxton Foundation do?" JB: "That's not what it was about." AL: "That's part of the feedback loop, that's the next phase." LC: "Is there a 'terms of reference' for this group?" AL: "Yes". LC: "So that might be useful to share" AL: "Reshare" LC: "Reshare, yeah, that might be a useful thing and then maybe the next meeting is a discussion about it, when you've got new people appointed." AL: "If we get our minutes out in a week with the action points and we will follow them up on a monthly basis." [GRO-A] "Just one important point to make. Although we're classified as campaign groups, we actually do try to represent core bodies within that, so you haven't got your 'out and out' campaigners, a lot of people come to us very privately and they don't want their names out." AL: "Of course, we understand that, ok, that's very helpful, thank you, I shall feed that back to board."

GW: "The one thing I wouldn't want to see is this overall meeting going adrift, I think I would want to see one overall meeting (called an AGM, whatever you like) but one meeting per year where everybody can attend. I have spoken with the other Partnership Group members (apart from [GRO-A] who arrived late) and we seem to be in agreement about that, what do you think [GRO-A] just one meeting a year?" [GRO-A] "The thing is, you could throw it open, but it doesn't sound like you are going to get a massive uptake." JB: "And that's the issue, and we would spend a lot of money doing that kind of event for very little uptake, I think that's the concern." GW: "I think that's what it comes down is the money more than anything, it's not about what's best for the beneficiaries, it's about what it's going to cost." AL: "Of course it's what's best for the beneficiaries, it's what they think and want." JB: "To run a meeting where there were virtually no people there in a big venue with lots of advisors on different things, I think would be probably a bit uncomfortable for everyone to be honest, so we need to look at whether there would be that uptake." [GRO-A] "Where we are looking at the number of primary beneficiaries, widows and so on, none campaigners, are we talking potentially the same people year in year out, or are you talking about maybe throwing it open and making reselecting itself on an annual basis?" AL: "Not annual because that would be unfair." LC: "Lots of Boards are 3 yearly, so 3 yearly would make sense." AL: "It would be unfair a year." [GRO-A] "Because that would give a chance for that kind of circulation." LC: "New people to come forward if they wanted to." AL: "And we will refer the meeting back to the board." [GRO-A] "Are you going to share this survey with us as well please?" AL: "Yes, we're giving it another couple of weeks Dave to make sure that we capture as many people as possible. We can send out with the minutes." VP: "Yes, we will be letting the beneficiaries know"

what the outcome is.” [GRO-A] “Are you sure the 16% are not government fudged figures?” AL: “No, they are not. Any other business?”

A.O.B

GW: “This is in terms of when people (and it effects quite a few people) when they apply for grants and they have been told that they’ve got to jump through all these hoops including census forms, seeing Neil Bateman, Jayne Bellis of Pennysmart, a lot of people for different reasons don’t want to do all that, so I feel there is a danger of those people falling through the cracks, they’re not going to get any help in the future because they are not prepared to jump through your hoops. So, what are those people going to do?” JB: “To be fair, I can think of very, very, very tiny numbers of people, in fact maybe just one, who don’t want to get that support when it’s offered to them.”

[GRO-A] “Can I ask if somebody accepts the help that’s offered – the financial advice and everything else, and goes away and then 6 months later find themselves in the same problem, what happens then? Do they re go back to the debt advisor? Are they refused help? Are they refused grants?” JB: “We would normally refer them back to the debt advisor.” [GRO-A] “And what if they refuse to go back to the debt advisor?” JB: “Again, it hasn’t happened.” [GRO-A] “But if they did?” JB: “We’d have to deal with it then.” [GRO-A] “What would the action be, would they be refused again?” JB: “There would have to be a discussion at that point, it hasn’t happened yet.” GW: “People have been referred (and I know this for a fact), referred to Neil Bateman and Pennysmart multiple times, so they will maybe see them, they’ll get the help they need from Caxton for a while, and then because they claim from Caxton, well you’ve got a problem with your income, so you’d better go and see Neil Bateman again. They’re put on a hamster wheel basically, you’re going round and round on this hamster wheel, and I know of one individual who has been on it four times and they are pressurised because they know full well that if they refuse to do these things, which Caxton are forcing them to do basically, because if they don’t do them then they’re simply going to have any grants stopped, they’re left with nothing. So they feel manipulated, they feel pressurised into doing something they don’t want to do.”

[GRO-A] “I agree, we do hear about cases like that and people whose circumstances really do not change in-between these referrals, and its like nothing has changed, what do you expect by having to go through the same process again and again.” LC: “That’s certainly is something we’ve heard occasionally, people feel like their situation hasn’t changed, they’ve been offered to see someone and there may have been a slight change in how they deal with whatever debt they’ve got, but actually the overriding thing that their outgoings are more than their incomings haven’t changed.” [GRO-A] “For some people, the balance between the income and outgoings is just never going to get resolved no matter how many times you refer them because their situation is just that dire.” LC: “So there is something about recognising for those people where it isn’t changing, what happens to them? If you can be clear about why things happen?” GW: “Because when they see Jayne Bellis and Pennysmart they are now given a form to say ‘can that information be shared with the Caxton Foundation’. We had a real fight at the beginning with the Caxton Foundation being set up because we found out that information (and this is quite serious) was being passed back from Neil Bateman and from Pennysmart, back to Caxton without the knowledge of the individual, so there are people out there who’ve had information passed back from Neil Bateman, certainly Neil Bateman, I think Pennysmart as well, back to the Caxton Foundation without their knowledge and that is outrageous. Now, they’re asked to sign a form

but it's got a bit of a leading question on the end of the form because it says 'can we share your information, if not it may affect the help we can give you in the future'. So if they want to remain private, which is perfectly understandable and reasonable, then again they are potentially not getting the help. The other question I have; is, if somebody thinks, right, I don't trust Caxton to transfer information (because I don't, I think possibly information does get fed back from these people) and they want to seek independent advice from say, Citizens Advice Bureau, or a debt advisor, or a local community benefits team, which I know there are several around the country, if they want to seek independent advice without going through Neil Bateman and Pennysmart, are they able to do it? And if they do, obviously they won't be providing the information back to Caxton, there would be no connection with Caxton, will they be penalised for doing it? JB: "Well a) of course they can do it because everyone is free to take advice from wherever they want it, I think if someone had gone down that route and maybe gone to a CAB advisor about something, if they then came to us asking for support with something, and I think there probably have been a few examples I can think of, people have fed back to us what the advice has been, so if for example sometimes as you know, if people are in a lot of debt, they get onto some pay plans and things like that, and people make us aware of how they've decided to deal with that situation and therefore what it means and what support they're looking to us from." GW: "You maybe don't realise, but you are actually creating a trap for people because however they do it, they could do it through the people that Caxton have or whether they do it independently and they don't share the information with Caxton, which is their perfect right, and you see that, that person is in the same situation (pretty desperate situation possibly) that they was in before they got the advice, then where do you go from there? You're trapped." LC: "Is there something where people could get a letter from wherever they've gone independently to say 'these people have taken advice, they are following the advice' and that's all you would need to know?" JB: "Yeah but what I'm say is, that's the kind of thing that we do get." LC: "So that happens and that would be ok? Maybe that's another of those things people are not understanding, that that would be enough, you wouldn't need the details of or on this payment plan, so again that information I think of, that would be enough to say 'they are following the advice they've been given independently' would be enough for you to say, 'ok, we can make an assessment on just that piece of information.'" CL: "There are a number of cases we've seen where people have, you know, had help and advice in consolidating their debts and we haven't, you know, that's fine, we don't ask them to demonstrate any further that's what they've done." LC: "So maybe that's a concern that people have that actually may not be founded on reality, but actually that concern is there." GW: "It comes down to detail of the information that's on the website again. I know people that have certainly fallen into that trap, I certainly have and I class myself as someone who has a reasonable understanding of this organisation, so if I have, then 'you can bet your life' there's going to be a lot of people out there who are having that problem." LC: "So if we are working on the frequently asked questions.." AL: "Yes." LC: "These are the things you think need to be included in that and we can share as much as possible." AL: "Thank you, that would be helpful."

GW: "One last thing, that is 2 hours really for this meeting, I've got a list of questions, and was wondering whether future meetings could go on for longer, say a full afternoon or the full morning, because a couple of hours really to discuss the number and the depth of the things we want to discuss, isn't really enough." AL:

"Ok, fine." JB: "You just have to bear in mind that if there are lots of kind of detailed points, that we might not have the information ready." [GRO-A] "Just one more point, you may not have the answer now, but you can always email me with it, could I clarify exactly what the process is you go through at the moment for the medication related ongoing payment.." AL: "I will, well we'll email everybody." [GRO-A] "so I can be clear whether it's the same for your first, your second, third, whether there are any terms and conditions whatever." JB: [GRO-A] will you just drop me an email with the questions you've got and then I can reply to you." [GRO-A] "It's just a general question; your basic policy what you go through, whether there is information required back, or whatever." AL: "Yeah, ok." [GRO-A] "Can I just ask, there was one thing, you were working on a data base on performance indicators." AL: "Yes, that's right." [GRO-A] "Is that ongoing? Is that being used now, or is that..?" JB: "Yes, that's just been effectively installed; we're just doing the final bits of data handling." VP: "Yeah, we're keenly going to make sure we can before we put it into the data base so it's imminent." [GRO-A] "So it's it imminent? Ok, we wait with interest to see how it works." AL: "Fine. Thank you very much and have a safe journey."