Witness Name: Gaynor Lewis
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Dated: 4 December 2020

INFECTED BLOOD INQUIRY

EXHIBIT WITN2368030

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Peter Stevens
Chairman
The MacFarlane Trust
Alliance House
12 Caxton Street London

31st October 2000

Dear Peter Stevens,

Re: Birchgrove's involvement in the Partnership Group

The Steering Committee of the National Birchgrove Group met recently and discussed our involvement in the partnership group run by the MacFarlane Trust. We felt that a number of points needed further clarification on both our side and that of the Trust. These points included the standing, purpose and professionalism of the Partnership Group as well as providing you with a better understanding of what 'Birchgrove' is and does.

The Purpose of the Partnership Group:

This may seem boring and bureaucratic, however bureaucracy is meant to ensure agencies work smoothly. When used well it can also ensure that decision-making is consistent, that power and responsibility for those decisions are clearly defined and that once decisions are taken a mechanism exists to ensure they are acted upon.

The strategic review group originally set up the group as "a means of response to those recommendations in the Strategic Review that required multi-agency participation in implementation". There were also a number of set tasks (from previous minutes). The first of these was to organise a series of meetings to provide registrants with feedback from the strategic review. The Groups' membership not strictly defined but an amalgamation of a group that organised a weekend for young positive haemophiliacs in Brighton, representatives from Birchgrove in Wales which also had long experience of organising events along with a few other individuals invited by Ann. Instrumental in its formation was Tim Hunt a Trustee at the time.

At the meeting in May 2000 it was proposed to amalgamate the group with the Strategic Response Group to create a group which would "emphasise partnership and user involvement". The group was to have new terms of reference and be a "forum for communication". At the August meeting we were presented with some aims and objectives. These were then forced through the meeting. For whatever reason it seemed important to have them 'passed' and 'agreed' in the meeting. Why were these heavy handed tactics needed for such an uncontentious document.

Noting the aim of the new partnership group, Birchgrove would like to know if it is considered as one of those "concerned with providing support and treatment to people with haemophilia and HIV" or as 2 registrants. The minutes from the last meeting imply that Birchgrove is one of the agencies providing support but the terms of reference define us as 2 registrants. Should Birchgrove choose to have non-haemophiliacs represent the organisation how would this be viewed by the Trust.

This issue of representation also affects the other registrants attending. Part of the new structure has people attending that fit into specific categories of registrant (Over/under 30, etc.) and partners without defining whether they are representatives for that category or there merely to bring their own views. If they are representatives of that group a system of choosing such representatives is necessary. If they are there purely to bring their own individual viewpoints this must weaken the ability of the partnership group to act as a formal "means of communication between the Trust's registrants, their partners and other dependents and all those concerned with providing support and treatment to people with haemophilia and HIV". Does this concern the Trust?

The Standing of the Partnership Group within the MacFarlane Trust:

We are very well aware that as members of the Partnership Group we are not Trustees and so do not have the same powers or responsibilities but equally we do not wish to waste time in a group which has no influence. The Partnership meetings have become (according to its new aims and objectives) a method allowing Trustees to regularly acquire the views of registrants. A number of previous half-hearted and half baked attempts have been made by the Trust to do this and so cynicism on the part of Birchgrove is to be expected. Indeed as the Trust is still working on the basis that registrants being Trustees is not permissible it is the only formalised method of allowing Trustees access to registrants views. This would seem to imply that as a regular and convenient system for gaining the views of registrants the Partnership Group should be very important to the Trust. Alternatively from a registrants viewpoint, it is the only formal method of input to the workings of the Trust. We would like to know how much value is given to views expressed by those people other than staff and trustees attending partnership meetings and what confidentiality rules are in place to protect the individuals expressing them

The revised terms of reference states that it "will report directly to the Trustees through the Chairman" and Birchgrove would like this to be spelled out more explicitly. To be blunt the previous chairman would leave meetings with registrants with a view contrary to everyone else in the room about how the meeting went and would then report his view of the mood of the meeting to the Trustees rather the on held by all other participants. How can we avoid this happening in the future?

The Professionalism of the Partnership Group:

Amongst the original tasks of the 'old partnership group' were to organise 4 feedback meetings. 2 of the feedback meetings occurred and the other 2 (suggested venues

Cardiff and Glasgow) stayed as agenda items for 3 or 4 meetings but did not actually take place as far as we can remember. One of the few other tasks set was to look at the issue of complimentary therapies for registrants, their value and the anomalous situation of a single payment to try them out but no on-going provision for registrants who found them helpful. As with the previous issue it no longer is an agenda item after being swallowed up by the Payments Review Group.

The old 'multi-agency response' group made the decision about membership of the new 'communication' group. In effect a non-elected body of people with no valid representative powers or high standing within the organisation decided how many Trust Registrants and of what type should attend this new group. Surely this should be a decision of the Trustees since they have formally convened this group and therefore should define who they wish to be on it. The trustees are the only people with the power to do this or to delegate this task. If they chose to delegate it what was the reason for delegating it to a group set up "as a response to recommendations in the Strategic Review that required multi-agency participation in implementation". The result of all this may well have been the same but at least then the decision-making process would be clear and the responsibility for the decisions made rest with the appropriate bodies. As it is we have a group with one widow on it and the reason for it being only one widow was made by a group that no longer exists or had any power or formal standing in the Trust and had indeed just been merged into the group that created it.

I could continue but in short as a group we are poor at ensuring we do our business well. This lack of effectiveness in discharging the tasks set the group and the ability to 'forget' items and tasks when they are to be carried over concerns Birchgrove greatly.

Yours sincerely,

Robert James
Chair National Birchgrove

14 November 2000

Robert James
Chair National Birchgrove
P O Box 9
Abertillery
Gwent NP3 1YD

Dear Robert

Thank you for your thoughtful letter, that arrived at the Trust office on the morning of the Partnership Group meeting. I hope that, since I had not read it until after that meeting, anything either in it or in this reply is not now either superseded or in need of amplification.

I have two principal objectives for the Partnership Group. The first is that it should be an effective means of communication, primarily "upward" – that is, a channel of views from the registrant members to the Trustees - but at times "downward", although generally anything that the Trustees need to say to registrants should be said to them all, not to a group thereof, however representative it might be.

My second objective is that it should be an informal, friendly forum, not bound by rules and red tape – not bureaucratic, to use your term. In achieving this I am having to battle slightly against the stream, and I value your letter as giving me an opportunity to justify my reason for wanting this.

I am disappointed that you feel that something that I have done, as Chairman, was to "force through" the Group's terms of reference. This is not something that I wished to do or felt that I had done. Maybe I should have been more determined in aiming for my second objective and not had any terms of reference in the first place – but at least you accept that they were not contentious, which I regard as a slight success.

However, you then hit on what is clearly at present a source of difficulty, which is the way in which we have chosen to define the Group's membership. As you rightly say, the original Group was formed to do a job a work in connection with the Strategic Review, for which a number of individuals were asked to participate, mainly because they had already shown themselves to be interested in and capable of action. It seemed sensible to draw on this pool of expertise and experience for the "new" Group, but to use the categories of members that had been defined at an earlier meeting to try slightly to reduce the number of people round the table, for no reason except efficiency of meetings.

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In this context I certainly did not seek to define Birchgrove in any way except as a convenient label to attach to some of those round the table. In retrospect, especially in the light of the suggestion that the Trust's beneficiaries in the "devolved" countries should also have some specific representation, I now believe that I made a mistake in trying to categorise the members of the Group. How – and if – to correct this mistake is a challenge. It seems now to me that it might have been preferable to determine the number of people that would make an effective and efficient meeting and then to ask for volunteers to make up that number (with allowance, possibly, for alternates).

This probably answers your broader point about representation. I do not see those attending as representing anybody else. They are there in their own right, as interested and articulate beneficiaries of the Trust whose views and suggestions can be helpful to the Trustees. In this they are similar to the prospective "user Trustee", who cannot be representative of the beneficiaries, in part or as a whole, but who will bring to the Trustee's meetings the experience of having haemophilia wit HIV infection.

It might be appropriate to mark at this point the difference in meaning between being "representative" of a wider set and being "representatives". I have all along seen members of the Partnership Group in the former sense, but I think others have taken the second meaning. There are probably instances where the use of the wrong term in writing has encouraged the latter view.

I do not believe that this weakens the ability of the Partnership Group to act as a means of communication, but since I had never seen its purpose in this as "formal" you and I might have grounds for further debate here.

So, communication, influence or what? As you know, your premise that the Trust is resisting the appointment of registrant Trustees is invalid, and I would expect that the vacancy currently to be filled by a Haemophilia Society appointment will be occupied by a registrant early next year. The last remaining hurdle of approval for this has been overcome with the belated receipt of clearance from the Charity Commission, so all this is necessary now is for one or more people to volunteer their names to the Society and for the Society then to go through whatever selection process they adopt. I will welcome this appointment, and see no reason why at least one more Trustee should not also be a registrant, although that is not, strictly, my call since the Trust has no formal say in the appointment of Trustees.

Having said that, I believe that any means of communicating to the Trustees the views, needs and other concerns of those they are trying to help are felt by the Trustees to be useful and valuable. It is for that reason, mainly, that, as I told the last Partnership Group meeting, I have written to all the Haemophilia Centre directors asking them to consult those of their patients who are registered with us to ask whether they would wish me to come and meet them and, if the response is positive, to assist in arranging a suitable meeting. The more our beneficiaries understand what the Trustees are trying to do and the constraints within which we operate, and the more we understand what people want and what their concerns are with the Trust, the better, in my view.

Maybe, if such meetings take place in sufficient number, the need for the Partnership Group to exist as a channel of communication will disappear. But we have not yet reached that stage. In the meantime, it is up to me, as Chairman, to report to the Trustees what is said at that Group's meetings that should affect their thinking and decisions. It is also up to me to do that in a way that satisfies those attending the Partnership Group. I am not going to propose a "bureaucratic" means of doing this. Either I deserve and get their trust, or I do not. I am happy to share, at the meeting, my conclusions of what I believe needs to be communicated, and to modify them if people (including Ann and other Trust staff) believe that I have the wrong end of the stick, but in the end it is my responsibility as Chairman both of the Partnership Group and of the Trust to be the interface.

I note your concern that the Group has shown a tendency to leave unfinished business lying around. The responsibility of getting certain things done is the subsidiary task of the Group besides that of communication. I agree, we have to work on this, allocate responsibilities and chase up action against an agreed timetable.

You conclude by broadly questioning the validity of the Partnership Group in its current form and purpose. My response, in similar broad terms, is that it is imperfect, but better than nothing. But we all have pressures on our time, and if it is preferable that the Group be superseded by other structures, such as my proposed meetings with a far greater number of registrants than can attend the Group, I am happy to bring it to an end. Certainly as far as getting specific tasks done its existence has identified a number of people who can work together effectively outside the Partnership Group; perhaps we should content ourselves with that.

Thank you, finally, as well for the explanation of Birchgrove. I had, of course, looked at the website, but your concise description is very helpful. In fact, your letterhead, which I had not seen before, is helpful as well – "special interest group of the Haemophilia Society" is quite specific.

My response to your letter turns out to have been long, but I hope it is helpful, and look forward to your reply. If it would help to pursue the discussion face-to-face, in order to reach a conclusion more rapidly, I am very happy to meet you wherever and whenever that can best be arranged.

With kind regards

Peter Stevens
Chairman