

As from
GRO-C
London: GRO-C

12 February 2014

Sam Younger CBE
The Chief Executive
Charity Commission
One Drummond Gate
London
SW1V 2QQ

Dear Mr Younger,

Re: The Macfarlane Trust ('MFT') Charity no: 298863

We write as former trustees of the above charity, having served 13 years and 7 years respectively before retiring at the end of last month, to express our concerns at the way in which the charity is being 'administered' by the present chairman and chief executive. It is only now that we feel able to write to you, having endeavoured and failed to correct perceived wrongs from within.

The Macfarlane Trust was established as a charity in 1988, at the behest of the UK Government, to benefit haemophiliacs, who were infected with HIV through contaminated blood products, and their dependants.

The present chairman was appointed by the Board in our absence in April 2012, when we expected him to be appointed only as interim chairman, pending the appointment of a chair sought through national advertising. The board of trustees ('the Board') had previously advertised the post but could not agree on a candidate.

Since his appointment, the chairman has failed to consult adequately, in our view, with the Board on matters of importance and upon strategy or to take trustees' views into account. The minutes of Board meetings, which he oversees, are, we believe, 'tweaked' towards his own agenda and he does not suffer being challenged lightly.

Both of us were elected to, and have been members for many years of, the main sub-committee, the National Support Services Committee ('NSSC') (Elizabeth Boyd as chair), which the chairman has tried to disband. Knowing that we were about to retire as trustees (our terms not being capable of renewal) and as NSSC members, steps have not yet been taken, in advance, to fill our places either on the Board or the NSSC. The chairman at a recent private meeting with us told us that he had asked a past NSSC member, who had resigned because he was usually at odds with other members of the committee, to return to the NSSC as chairman. When we pointed out that it was for the NSSC to appoint its own chair, he retorted that it was, of course, subject to ratification by the NSSC!

The chief executive is a recent appointment (January 2013). In 2011, the UK Government, through the Department of Health ('DoH'), which is the sole source of

funding for MFT, 'set up', following the Archer Inquiry, the Caxton Foundation ('Caxton'), a charity operating out of the same offices as MFT, whose beneficiaries were infected with Hepatitis C by contaminated blood products. The DoH required that Caxton took over the leasehold premises and all the staff previously employed by MFT and it was agreed that MFT's beneficiaries would be protected and serviced under a 'service level agreement' entered into between MFT and Caxton but, importantly, that a chief executive would be appointed who would be chief executive of both MFT and Caxton. The chairman was, at one time, a trustee of both MFT and Caxton, but was required to stand down as a trustee of Caxton as a condition of his appointment as chair of MFT.

Recently a Business Case for additional funding was submitted to the Department of Health, drafted by the Chief Executive. A Business Case was also submitted on behalf of Caxton, again drafted by the Chief Executive. The DoH has apparently indicated that it wants 'cross over' or parity between the two charities, but as several trustees of MFT pointed out, prior to the submission of the Business Case on behalf of MFT, the primary beneficiaries of each charity have very different physical and mental issues.

None of Caxton's beneficiaries have HIV and many are not haemophiliacs. All of MFT's primary beneficiaries have haemophilia (with all its complications affecting joints) and HIV, and some 90% also have Hepatitis C, although they are not entitled to be beneficiaries of Caxton. Furthermore, no account appears to be taken of MFT's primary beneficiaries' current health issues, brought about by 30 years of ingesting toxic cocktails of drugs to counter the effects of these three conditions, nor of the stigma that they have long suffered by being HIV positive. The medical conditions affecting most of MFT's beneficiaries warrant a substantial differentiation in financial support, which the chief executive appears to ignore, as does the chairman, neither of whom want to 'rock the boat' with the Department of Health. The chairman was formerly a chief executive of NHS trusts and, it is believed, currently has consultancy arrangements with the NHS and/or the DoH, which may or may not have a bearing on the issue.

When this differentiation was raised at the last Board Meeting and a request made to amend MFT's Business Case, the chief executive said that she was unwilling to make such changes as it would affect Caxton's Business Case for parity. She was supported by the chairman. It has subsequently been pointed out to the chief executive (and chairman) that this demonstrates a clear case of conflict of interest on the part of the chief executive and a meeting with the chief executive was proposed back in December 2013 but has, so far, not occurred (and is unlikely to now that we are no longer trustees). A recent meeting with the chairman (which the chief executive did not attend although she was expected to) resulted in us being accused by the chairman of a 'witch hunt'. This meeting was also attended by a current trustee.

We are concerned for MFT's beneficiaries. In these constrained times of Government cutbacks, and given that the DoH is the sole source of income for MFT and that there is seemingly only a single pot of money to cover both MFT and Caxton, it is imperative, in our view, that MFT's case to the DoH is unfettered by a conflict of interest on the part of the chief executive and the apparent conflict that the chairman may have.

There have been other issues of concern, which we do not propose setting out in this letter but which we are happy to expand upon.

We also propose writing to the Secretary of State for Health pointing out our concerns.

We look forward to receiving your comments.

Yours truly,

Elizabeth Boyd

Russell Mishcon

Note:

Elizabeth Boyd was appointed a trustee of MFT by the Secretary of State for Health and worked at the Royal Free Hospital Haemophilia Centre as Benefits Adviser from 1985 until 2011.

Russell Mishcon is a practicing solicitor and was appointed a trustee by MFT. He is the author of a dissertation for a Masters in Voluntary Administration (awarded with distinction) entitled:

The Strategic Challenges Facing the Macfarlane Trust:

The effects of demographic change and lack of Government funding on haemophiliacs infected with HIV/Hepatitis C by NHS administered contaminated blood products.