

## **DH/MACFARLANE TRUST – Update Meeting**

Tuesday 28 October 2008 at 2:30pm – Room 501, Wellington House

Attendees: Macfarlane Trust: Christopher FitzGerald (Chair), Martin Harvey (Chief Executive) and Nick Fish (Assistant to Chief Executive)

Department of Health: Brian Bradley and Glen Clarke

### **Discussion**

#### **1. Macfarlane Special Payments Trust No. 2 (MSPT2) Category (g)**

Christopher FitzGerald stated his view that there is a need for a change to Category (g) in the MSPT2 Trust Deed. He thought that the Department should recognise this claim as a means of providing assistance to people who, for whatever reason, had missed the opportunity to claim at an earlier time. He added that the DH's reason for not authorising payments to claimants because the Trust Deed does not allow it to do so is not an argument against helping these claimants. Brian Bradley remarked that DH are not able to make any payments to these claimants under the terms of the Trust Deed. He recognised that the Trustees and DH together could take action by changing the Trust Deed and would be prepared to consider whether this was appropriate. Martin asked if the DH would consider making payments to just the children of primary beneficiaries who had been excluded. Brian confirmed that the DH would consider this provided it was affordable. Christopher said that the Trust would carry out further work on this matter to establish the numbers involved and get back to DH. Martin mentioned that he would talk to Mr Stevens and Mr Spellman of the MSPT2 about this issue. He added that both DH and the Trust needed to continue to work together in the present spirit of partnership.

#### **2. Macfarlane Trust current Funding and Reserves Policy**

Christopher referred to the position that there would be no increase in the Trust's funding from DH for 2009/10 and for the following two financial years. He reiterated that this amount of funding would not be enough for the Trust to meet its objectives adequately, although he understood the Department's position. Martin suggested that reverting to an annual settlement at the start of the year would be very beneficial to the Trust's finances, especially in the context of the indicative flat funding. Brian said that he would look into this and that DH could be sympathetic to this request. Christopher added that if the DH accepted this request this would be seen as a positive demonstration of the DH's support for the Trust and the spirit of partnership. He mentioned that the Trust's investments had, inevitably, been affected by the financial market turbulence but there had been no affect on payments to the beneficiaries. Christopher stated that the Trust has endeavoured to utilise and reduce its reserves with a view to a policy of

maintaining six months forward spend. He pointed out that if the Trust does increase their regular outgoings than the reserves will need to be at a higher level. Martin mentioned that the Trust were grateful for Brian's efforts on the caveated assurances that he was able to give regarding the Trust's funding and that the Trustees were content with the new funding policy. Christopher said that the Trust would continue to make the case to the Department for an improvement in their funding and noted that the Trustees would continue to move money around for their beneficiaries.

3. **Disbursement Policy**

Christopher mentioned that all affected beneficiaries and their dependents are entitled to relief and their needs being met. He added that the Trustees are using greater targeting, so that more funding is to be provided to the people in the greatest need of financial support. The Trust has all the regulatory requirements of a 'normal' discretionary disbursement charity but with a unique beneficiary group. The Trust is bound by Charity Commission guidelines and must therefore take steps to satisfy their rules and regulations. Nick Fish said, in response to a question, that about 10 registrants die each year. Hepatitis C is the main killer and just in the last few weeks two deaths had been caused by hepatitis C. Christopher said that there had been between three to four deaths a quarter over the last 12 months. He added that the average age of a beneficiary is 42 years old and their life expectancy was the same as most healthy people.

4. **Long Term Funding**

Christopher mentioned that the Trust had been carrying out some work on long term funding. He said that in about a month's time they could bring to DH graphs and other documents to support the need for payments to all the beneficiaries for the rest of their lives. The Trust will give Brian all the details about this in a report. Martin intended that the report on long term funding would be both informative and instructive. If asked, the Trust simply inform beneficiaries that the issue of long term funding is being thought about.

5. **Medical Trustee appointment (DH appointees)**

The recent Medical Trustee interview with Dr Vanessa Martlew had been very positive. Brian noted, as previously advised, that the Department will have to go through the proper processes for appointing a new Medical Trustee. Christopher suggested that it would be helpful to reach a decision on who will be appointed as the new Medical Trustee by the end of January 2009. Brian confirmed that this should be possible depending on the number of applicants.

Martin put forward that Mrs Elizabeth Boyd had informed him that she would be delighted to be re-appointed as a Trustee after her term finishes at the end of March 2009. Brian replied that this should be fine and would be handled at the same time as the Medical Trustee appointment. Martin said that he would e-mail Brian to prompt him to take action on this.

Christopher mentioned that if an existing Trustee wished to stay on for two more years he would be happy to re-appoint them for the four year term; this may even help to spread out the re-appointment dates. Brian thought this would be acceptable.

**6. Any Other Business/Related Matters**

Christopher referred to the option of a merger between the Macfarlane Trust and the Eileen Trust. This was still the DH's preferred option although Brian acknowledged the arguments put forward by the Eileen Trust regarding the loss of their own identity if a merger was to take place. Christopher felt that a merger is not a practicable possibility in the Macfarlane Trust's eyes for a number of reasons. Martin remarked that the size of the Eileen Trust is quite small and there are 24/25 beneficiaries for the Trust. He and Nick referred to the option of moving the Eileen Trust's Secretariat out of Alliance House. Brian mentioned that DH are more inclined for the merger to move ahead and to keep the Eileen Trust in Alliance House. If the Trust were to accommodate the ET's administration then the case worker would inevitably have to be made redundant. Christopher added that the major stumbling block to the possible merger would be money and the inequalities that exist between the two trusts. If the DH were to fund the equalisation of payments to beneficiaries, including that of the capital payments made in the late 80s/early 90s, and the merger did not cost the Trust anything then he would be happy to try and influence the other Trustees and the beneficiary community. Brian said that the Eileen Trust needs to provide DH with all the sums of the merger. He added that the merger might be more cost effective than buying out the Eileen Trust.

Potential dates for the next meeting were discussed and this may take place after the Archer Inquiry reports or in six months time.

Nick mentioned to Brian that he had received correspondence from the Hepatitis C Trust requesting to see the Skipton Fund Administrator's Report and the Appeals figures; he handed a copy of the report to Brian. He asked whether the Department was content for the report to be put in the public domain. Brian said that he would look into this matter and respond to Nick.