

The Macfarlane Trust

In May 2016, the board appointed Alasdair Murray, a Trustee since February 2014, as the new Chair of the Macfarlane Trust. This followed the resignation earlier the same month of Roger Evans, who had been an MFT Trustee since January 2007, and Chair since April 2012. Roger made a major contribution to the development of MFT during his years with the organisation, and had also been one of the founding Trustees of The Caxton Foundation, one of MFT's sister organisations, when it was set up in 2011. During the year, Eileen Jackman also retired, having served a full three year term as a Trustee.

In the run up to the start of the new financial year, the MFT board continued to press the Department of Health (DH) for an increase to its annual financial allocation. However, additional funds for 2015/16 were not forthcoming and the allocation remained frozen at £2.2 million, in spite of clear evidence that this was insufficient to meet the needs of beneficiaries. The board has been determined to maintain the level of support it provides to beneficiaries, even though the DH allocation has not been adequate to do this. In April 2015 the board therefore decided to continue its policy of supplementing the DH allocation from funds held in reserve. The MFT board has made it clear to DH that supplementing the annual allocation from reserves cannot continue indefinitely, as the level of reserves is reducing year on year. Consequently, the MFT board continues to press for an increase in annual funding to an adequate level.

In 2015/16 the political focus on contaminated blood, which had started the previous year, increased, with the publication by DH in January 2016 of a long-awaited consultation on reform of financial and other support to those infected with HIV and Hepatitis C as a result of contaminated blood, and their families. MFT's analysis of the proposals set out in the consultation gave significant cause for concern, as it appeared that MFT beneficiaries who were mono-infected with HIV, or co-infected with HIV and Hepatitis C at Stage 2 were likely to be worse off financially under the new proposals. MFT beneficiaries who were co-infected with Hepatitis C at Stage 1, who would be eligible to apply for an individual health assessment under the new proposals, might be better or worse off, depending on the level of payment they were to receive as a result of the assessment. With regard to the bereaved, beneficiaries might be better or worse off, depending on whether or not someone chose a lump sum, and the level of this, and depending on what the Government envisaged by "ongoing discretionary support" for those who opted not to take the lump sum. The consultation document also proposed replacing the existing Alliance House organisations - including MFT - with a single entity.

In January we therefore wrote to all beneficiaries with an analysis of the proposals, encouraging them to read and respond to the consultation, whether they agreed with the proposals or not, to ensure the Department of Health heard the views of as many of those affected as possible.

During 2015/16 MFT worked closely with the other four Alliance House organisations which support people infected with HIV and Hepatitis C as a result of contaminated blood on matters of common interest. The Chief Executive and Chairs of the five organisations met with Jane Ellison MP, Under Secretary of State for Public Health, before the consultation was launched. We also held several meetings with Department of Health

officials. Following the launch of the consultation, MFT and the other four organisations submitted a joint response to the proposals, highlighting the many ways in which the proposals would disadvantage beneficiaries if they were implemented.

On 13 July 2016, during David Cameron MP's final Prime Minister's Questions, the Government announced its response to the consultation. The model of future support it announced applies to England only. There are some improvements to support for beneficiaries compared with the original proposals, including an increase to non-discretionary payments (currently made through the Skipton Fund and MFET), the introduction of regular payments for those at Stage 1 Hepatitis C infection, and the retention of the link to CPI. The announcement that discretionary support will also be retained was welcomed, although until there is further clarity on this, it is not clear whether any beneficiaries will be disadvantaged by then new arrangements; there are concerns that some will.

During 2015/16 the Scottish Government established a Review Group to examine the financial support provided to those infected in Scotland, and their families. In March 2016 the Scottish Government announced that it would be adopting the recommendations made by the Review Group to increase financial support to those infected in Scotland. The model of support which has been adopted for Scotland is considerably more generous than that which currently exists in the rest of the UK, and the payments are greater than those announced for England. At the time of writing, it is not known which model of support Wales and Northern Ireland will adopt. However, there will no longer be a unified system of support across the UK.

The Government also announced that for the future, there will be a single scheme administrator which will become operational during 2017/18. At the current time, we have no further information regarding the future of MFT, but we are hoping that the Department of Health will clarify the future administrative arrangements as a matter of urgency, and work in partnership with the Alliance House organisations, including MFT, to implement a new scheme administrator which retains the knowledge, experience and expertise of the existing group of dedicated staff.

Jan Barlow
Chief Executive, Macfarlane Trust
August 2016