

The Macfarlane Trust

During 2014/15 the Trust Board membership experienced a year of relative stability. Paul Biddle and Alasdair Murray were appointed as Trustees in early 2014 and their finance, business and political experiences were invaluable to the Trust during the year. Patrick Spellman's term of office was due to terminate in January 2015, and we were very pleased that he agreed to stay on the Board for a further two years. In January 2015 Alan Burgess resigned as a Trustee after almost six years.

In late 2013 MFT submitted a robust business case to the Department of Health in support of a substantial increase in its allocation for 2014/15. This was done in the climate of economic austerity and, unfortunately, the Government could not agree to increase the allocation. Nevertheless, it was agreed that the allocation should remain at £2.2 million, the same as for the previous year. This coincided with a reduction in funding for many other areas of Government-funded work and this was of some consolation. In April 2014 the MFT Board decided to continue its policy of supplementing the Government allocation from MFT reserves in order to be able to continue to support beneficiaries at the same level as in previous years. In the case of regular payments to primary beneficiaries, we were able to increase the payments in line with CPI.

During 2014/15 the Board reviewed its approach to grants for beneficiaries and made a number of changes. Firstly, the National Support Services Committee (NSSC) was replaced with a Grants Committee. We also responded to criticisms from beneficiaries who felt that the criteria used to decide whether to allocate grants were not transparent. During the year we therefore introduced and published clear guidelines setting out what the Trust is, and is not, able to support in relation to grants. We also introduced a standard application form and application guidelines to assist beneficiaries when submitting grant applications. The Board also agreed to delegate more authority to the staff team for considering and approving, where appropriate, certain grant applications where they meet agreed guidelines approved by the Board. All of these changes have enabled us to streamline the grant application process and reach much faster decisions on grant applications.

During the course of 2014/15, the system of support which has been constructed by successive Governments over the last 25 years for those infected with HIV and Hepatitis C was in the political spotlight.

The All Party Parliamentary Group on Haemophilia and Contaminated Blood (APPG) conducted an inquiry into the existing system of support provided by MFT and its four sister organisations based at Alliance House: the Eileen Trust, MFET, the Skipton Fund and the Caxton Foundation. MFT, along with the other four Alliance House organisations, were pleased to have the opportunity to assist with the inquiry, including distributing the letter about the inquiry survey to approximately 2000 people registered with the five organisations, and providing as much information as possible, both at a meeting with the APPG in September 2014 and subsequently by letter and email.

Whilst there was a tendency in the report to focus on, and quote, negative, rather than positive, comments made about the organisations, we felt that the report overall was balanced and acknowledged the constraints – particularly the financial constraints – which give rise to much of the criticism about the way the organisations operate. The Alliance House organisations are well aware of the dissatisfaction of some beneficiaries with the fact that successive Governments' response over the years has been to set up five organisations – two companies and three charities – to provide non-discretionary and discretionary support as opposed to providing any final settlement. Beneficiaries' dissatisfaction is compounded by the fact that the charities are not funded at a level which could meet many beneficiaries' expectations, and also that they have to be able to determine charitable need when making any form of discretionary payment. Therefore many of the criticisms in the report were not unfamiliar to us. However, we were pleased to see that in the survey, the majority (65%) reported a positive or neutral experience of engaging with us. We are committed to continuously improving our performance and responsiveness, and the range of services and advice that we offer, subject to funding. The report also acknowledged that the beneficiary community overall is divided in relation to the type of support that should be provided to those that were infected with HIV and Hepatitis C.

On 25 March 2015, the long-awaited and much-delayed Penrose Inquiry published its final report. The independent public inquiry had been established in Scotland in April 2008 to look into the circumstances in which patients treated by the NHS in Scotland became infected with Hepatitis C, HIV, or both, through the use of blood or blood products. The report made only one recommendation – that everyone in Scotland who had a blood transfusion before 1991 should be tested for Hepatitis C.

Following the Penrose Inquiry report launch on 25 March 2015, the Prime Minister made an apology to all those who had been affected during Prime Minister's Questions in the House of Commons on the same day. He also announced that up to an additional, one-off £25 million would be made available in 2015/16 "to support any transitional arrangements to a better payment system". Subsequently, it has been announced that there will be a public consultation in the autumn of 2015 on the future arrangements for financial support, but there has been no confirmation as to how the £25 million will be spent. A separate consultation on future arrangements for those who were infected in Scotland has been undertaken during the summer of 2015; this is due to report in the autumn.

Jan Barlow
Chief Executive, Macfarlane Trust
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