

Macfarlane Trust

The Macfarlane Trust was established many years ago to distribute monies provided by the Department of Health on a discretionary basis to patients with bleeding disorders who had been infected with HIV as a result of transfusion of blood components. In the spring of 2009 the proportion of these funds dispersed as regular non-discretionary payment to beneficiaries was substantially increased as instructed by the Department of Health in its initial response to the Archer Report. The smaller amount of remaining monies continued to be used on a discretionary basis to provide advice and to support individual requests and social activities organized between the Trust and the Haemophilia Society. The core staff at the Trust had worked very hard over a relatively short period of time to make the appropriate modifications so that recipients could benefit from their increase in income at the earliest opportunity. As additional funds were now available efforts were made to seek out relatives of deceased beneficiaries who might be in need of financial support in the absence of their deceased partner or relative. As the Trust had clearly been set up to supervise the dispersal of monies on a discretionary basis it appeared in April 2010, therefore, that the work of its administrative staff might be expected to decline significantly with time.

During 2010/2011 energetic discussion continued at Board Meetings about the structure of the new “slimmed down” Trust Board whose work would be simplified by the reduction in the need for discretionary payments as most beneficiaries were now receiving a more generous regular income. As there are three sources of input – from the Haemophilia Society, from the Department of Health and from the Board itself - it is necessary to seek approval from the external sponsors of their reduced representation in the future. The new Trust Board is likely to be formed in April 2012 to coincide with the retirement of its current Chair.

There were other developments in 2010/2011 which have secured the position of the administrative staff in the Trust office who have recently been asked to take on considerably more work in connection with transfusion acquired hepatitis C.

Following the general election in May 2010 the coalition government reviewed the previous response to the Archer Report and acknowledged the failure of the previous administration to recognize the lack of regular benefit provided to those with transfusion acquired hepatitis C in comparison to those with HIV. Early in the New Year they announced a scheme for regular payment to those with chronic liver disease caused by hepatitis C which is comparable to that paid to those with HIV- and the co-infected are to receive both. Such non-discretionary payments may be made by the Skipton Fund. In addition there has been a look-back exercise undertaken to provide compensation posthumously to the families of those with transfusion acquired hepatitis C whose relative died before the compensation scheme had been introduced.

There is also to be established a new body to make discretionary payments to those with chronic hepatitis C and it is expected that the Caxton Fund will be in a position to make such awards from autumn 2011.

The Department of Health has asked the staff of the Macfarlane Trust to administer all these payments on its behalf. In order to achieve this more space and staff will be required and its operation is, therefore, to be significantly expanded in 2011/2012.

It had been intended that the Board would be represented at the World Federation of Haemophilia in South America in July 2010 but unfortunately both its representatives were seriously indisposed just before the event and were unable to attend. In fact, Martin Harvey, the energetic Chief Executive of the Macfarlane Trust was very seriously ill requiring several months in Intensive Care – only to return to work in January 2011. The remaining staff are, therefore, to be congratulated on completing all the work involved in these changes on a skeleton staff in a most efficient and professional manner.

Dr Vanessa Martlew
Medical Trustee, Macfarlane Trust
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