

## Haemophilia Society

The Society has continued to make significant progress in 2010-11 and we are pleased to say that our financial position looks significantly better than two years ago.

Over the past eighteen months we have been reviewing our governance and at a General Meeting in late 2010 significant changes were made to the Society's Memorandum and Articles of Association. The emphasis is still very much on being a patient-led organisation but we hope that the changes will mean that that we can secure the right skills to run the organisation efficiently and effectively.

The Society has continued to run a wide-range of services including the website, the information and support line and activities for young people. There has been significant development in our work for older people with bleeding disorders in particular the Activate project (funded by the Macfarlane Trust). In addition our youth leader's project is now firmly established with the group playing a major role in developing and supporting our work with young people and families. In Scotland we opened our office in Edinburgh and established Haemophilia Scotland.

As part of the *Get Involved Get the Best Project* we launched a new booklet called *Your Services*. Based on the Haemophilia Alliance's National Service Specification, the booklet guides patients and their carers on what they can expect from a comprehensive care service. We have worked with local specialist commissioners in a number of areas and will continue to work regionally within the new structures. The Society has also been represented on a number of UKHCDO working groups including Clinical Outcomes and the Triennial Audit.

In early January we responded to the Coalition Government's review of support for those infected with contaminated NHS blood products. Whilst we recognised that progress has been made, the new arrangements still fall some way short of what many would consider closure. We continue to press the Government to reconsider their decisions and to try and ensure that the new arrangements are implemented fairly. The Society is a core participant on the Penrose Inquiry in Scotland.

Although our financial position is much improved we continue to operate on tight margins and the Society's Board is striving to ensure we have sufficient funding for our services and to implement longer term plans for income generation.

Once again we have welcomed many opportunities to work with the UKHCDO and its members as we look to achieve high standards of care and treatment for people living with bleeding disorders. We look forward to this continuing in 2011-12.

Chris James  
Chief Executive  
July 2010