

Haemophilia Society

During 2011-12, the Society's Board of Trustees commenced a review of the Society's Vision and Mission, together with its Strategy. The timetable was to have a new version of these in place during 2012, to incorporate a clear statement of priorities. It was agreed that a key aim of the strategy should be to create a virtuous circle whereby the Society improved its two-way communication with members, encouraged greater participation by members in the activities of the Society, and improved fundraising.

As part of this review the Board decided that that the Society should develop a public policy statement on Contaminated Blood to support its lobbying of Government. Following development work up to March 2012, a draft policy was agreed by the Board of Trustees and presented to the membership for comment over the summer of 2012, and it is intended that a final policy will be agreed by the Board during 2012.

We have continued to develop and provide our key information and support services for all people with bleeding disorders. This including on-going development of our website to improve access and to review the information provided.

We have brought people together by running events for children and families and providing opportunities for peer support including activity events attended by 40 young people and children.

Our Youth Leaders have been involved in the running of Society activities and we have recruited 5 new young people onto the programme.

Our new Buddy Award was highly successful with a launch in the Houses of Parliament attended by over 100 families and awards event at London Zoo. Over 34 Awards were given to siblings, friends, haemophilia nurses, parents, carers and teachers.

There has been an increasing focus on our work to reduce isolation for older people with bleeding by providing social networks and the expanding of the Activate Project through information and support activities. We are pleased to be working with Basingstoke CCC and UKHCDO to develop Guidelines for the care of older people with bleeding disorders

We have worked in partnership with the United Kingdom Centre Directors' Organisation and Haemophilia Nurses Association to develop the Triennial Audit process and in particular the patient review.

In Scotland we have engaged with the Penrose Inquiry in Scotland as a Core Participant and held a highly successful reception in the Scottish Parliament.

We have played a significant role on the Haemophilia Task and Finish Group in Wales and been instrumental in establishing an All Party Group on Haemophilia in the Welsh Assembly.

We have engaged with policy makers and commissioners by promoting the Fit for the Future and Newcastle Recommendations including contact with MPs, Peers, specialised commissioners, press work and supporting members in establishing contact with local politicians.

As part of the Haemophilia Alliance we met twice with the Department of Health to raise and resolve treatment and care issues. We have also established a more robust process of raising and resolving issues in those meetings.

We have been very grateful for UKHCDOs support and encouragement in our Bid to host the World Federation of Haemophilia Congress in Glasgow in 2018.

In the coming year we will be embarking on an important project to improve and develop our links with Haemophilia Centres so that with improved relationships we can better serve all people with bleeding disorders.

Chris James
Chief Executive
September 2012