

Haemophilia Society

The Society remains committed to the belief that the active involvement of informed patients in their own care will improve clinical outcomes.

During 2012/13 the Society progressed in its core mission of supporting all people affected by bleeding disorders through provision of information and services, building community and mutual support, influencing government health and welfare policy, and involving people in making decisions about their own care.

We continued and developed our provision of information through our website, social media, and printed channels. We updated and added to our leaflets and made them available electronically. We also continued providing support through our information and benefits helplines.

Our activities to support people with inhibitors included maintenance of our information website, and running a residential weekend. We also held family and children's weekends, which have a key role in providing children with peer support.

In the year we put a great deal of work into developing our Local Groups, many of which had become moribund. The improvement in treatment over the years has meant that patients who used to see each other at clinics now self-treat at home, and the sense of local community which once existed has to some extent been lost. We believe in the value of an active Local Group providing mutual support on practical issues – often arising from looking after young children with a bleeding disorder – and engaging constructively with the local Haemophilia Centre. We saw encouraging progress during the year on the strengthening of Local Groups and the creation of new ones, and we shall be working further on this as part of our strategy.

A major feature of the year was the impending reorganisation of NHS England. We were active participants in the Clinical Reference Group for Haemophilia, which is setting the new Service Specification.

We also participated in the 6-monthly meetings between the Department of Health and the Haemophilia Alliance. These meetings allow discussion and resolution of current issues and are one of the few forums where governance for the four devolved health services comes together. We are grateful to the UKHCDO for its involvement, and we believe that we should work to enhance the effectiveness of these meetings for the benefit of patients, clinicians, and health services alike.

We continued our engagement with UK Centre Directors on the Triennial Audit. Our "Get Involved Get The Best" scheme encouraged patients to become involved in these audits as an example of taking responsibility for their own care. A development in the year was our explaining to patients the benefits of using Haemtrack to report on their own treatment; this was intended as a step towards the Society's educating and encouraging patients to improve their compliance with treatment.

We commenced planning for a series of visits by the Society to Comprehensive Care Centres. The intention is to visit every CCC on a two year rotation and to build close relationships with the staff so that we can help identify and resolve local problems; ideally, the visits will involve Society members.

The need to engage with four devolved health services puts a strain on the resources of the Society; this is an area for future development. The Society was a Core Participant at the Scottish Government Penrose Inquiry into contaminated blood. In Wales we were active with the Cross Party group on Haemophilia and Contaminated Blood at the Welsh Assembly and the All Wales Advisory Group.

In Westminster, the Society acts as the Secretary to the All Party Parliamentary Group on Haemophilia and Contaminated Blood, and in the year we assisted the revitalisation of this Group under new leadership.

A highlight of the year was our winning the vote to host the 2018 Congress of the World Federation of Hemophilia in Glasgow. This is a major international conference held every 2 years which attracts some 5,000 clinicians, researchers, and patients, and other interested parties. It will provide a showcase for the UK clinical and research communities including the Scottish Haemophilia Centres, as well as giving UK patients a window on current developments in care and treatment. We will involve the UKHCDO in our planning for the event. As icing on the cake, Belfast won the vote to host the Conference of the European Haemophilia Consortium. This is a somewhat smaller event, but will also provide an opportunity to see and hear leading researchers.

Sadly, the Society's long-standing President, Lord Morris, died in August 2012. Our members will best remember him for his robust fight for those affected by the contaminated blood products supplied by the NHS. However, he was also strongly active on our behalf on health issues. We are fortunate that Baroness Molly Meacher has agreed to become our new President, bringing her own strong background in healthcare.

Bernard Manson
Chair, The Haemophilia Society