

## Haemophilia Society

2013/14 was very much a year of change for the Haemophilia Society with the departure and replacement of the CEO and the reorganisation of the staff structure to give effective support for implementation of the Society's strategy. We believe that our necessary investment of time in these internal matters has put the charity in a much stronger position to meet our members' needs going forward.

Chris James resigned from his post as Chief Executive in July 2013; the post was filled for six months by an interim CEO, Rachel Youngman. During her period as CEO, the Board finalised the charity's new Vision and Mission statements and agreed the review of the Strategy and of staff requirements, which Rachel developed. This led to a restructuring and to the departure of many of the existing staff.

After a formal recruitment process, Liz Carroll was appointed as the new Chief Executive in November 2013 and joined in January 2014. Liz had previously worked in senior roles in a major cancer patients' charity after starting her career as a nurse; this included experience in haematology. She gradually recruited staff to fill the new posts and began work on delivering the new strategy. The immediate priorities were to stabilise the Society after all the change and to ensure it was effective, efficient and sustainable for the future.

A particular issue has been funding. Our £100,000 annual grant from the Department of Health ended in March 2013 and we also saw significant reductions in other income, particularly grants from pharmaceutical companies. As result, we needed to make major savings and to develop new sources of income. The new staffing is at a lower cost and we are working to reduce premises costs by finding cheaper accommodation for when our lease ends in December 2014.

The updated Vision and Mission statement allowed us to improve our communication with members and other stakeholders and to improve the alignment of our activities with our Mission. For example, we reinforced our commitment to working for all bleeding disorders and we are improving our focus on measuring outcomes from activities so as to be able to prove value for money to funders and members.

### **Vision**

Wellbeing for everyone with a bleeding disorder.

### **Mission**

For all those affected by bleeding disorders, to:

Provide information and services;

Build community and mutual support;

Influence government health and welfare policies, including advocating for those impacted by contaminated blood;

Involve people in making decisions about their own care.

The prolonged period of change has had an impact on our ability to deliver as much as we would hope during the year, but we were nevertheless able to continue services and to initiate new activities. We held our first event for women with bleeding disorders and ran improved weekend events for new families. We put considerable effort into rebuilding our website to make it accessible and user friendly and to provide a more powerful resource for those seeking information; this work is ongoing at the year end. We also made progress in strengthening our structure of Local Groups.

As well as developing our website, we have continued to provide information and support via the phone, email and via social media. Activity on our three Facebook pages and on Twitter has significantly increased with these becoming a major source of information and peer support for the community. We also reviewed several of our information publications. We continued to get positive feedback from members on our membership magazine, HQ, and we have worked to extend the range of articles included. We also agreed to develop our first public awareness campaign for women with bleeding disorders to be delivered in June 2014.

We held successful children's activity weekends and ran a very well evaluated pilot service for families with a newly diagnosed child. The service ran over a residential weekend where parents could hear from medical and nursing experts about bleeding disorders, treatments and developments, as well as having facilitated small group sessions to discuss and share thoughts and feelings about the psychosocial aspects of coping with a child with a bleeding disorder. The positive feedback from this pilot will be written up and presented and will inform the planning of future weekends for newly diagnosed families.

We continue to grow and develop our Local Groups, with several new groups opening and long standing groups becoming reinvigorated. Several new groups have already run activities, supported families and raised funds for the charity. Other groups continue to focus on campaigning on contaminated blood issues. It remains a strategic goal to have active Local Groups throughout the UK.

Following the restructure of NHS England, the Department of Health (DH) has lost all its direct authority over the NHS. This has complicated our advocacy, as instead of having one central contact we have to network widely with and within the four Nations. The meetings between the DH and the Haemophilia Alliance have stopped and we have been looking at how we can best work with the different structures within the NHS

We have developed positive working relationships with NHS England and with the Specialist Clinical Commissioning Group. For example, we have representation on the Clinical Reference Group which sets standards for care and we were involved in the national tender for Factor 8. Through our trustee, Lynne Kelly, we worked closely with NHS Wales but the need to engage with four devolved health services continues to put a strain on the reduced resources of the Society and we are considering how we manage this challenge, particularly in Northern Ireland and Scotland where we are looking to find local people who could assist. We continue to cooperate across many areas with the UK Haemophilia Centre Doctors' Association (UKHCDO) and with the Haemophilia Nurses Association (HNA). We also maintain relationships with the DH.

During the year we put considerable effort into finding funding and academic support for a "Burden of Illness" study on severe haemophilia. The background is that the National Institute for Health and Care Excellence (NICE) decides which treatments the NHS will fund

on an analysis of costs versus directly observable benefits to health. However, for a chronic condition such as haemophilia, there can be wider benefits to people who would otherwise suffer additional problems such as missing work or school or necessitating carers to miss work to look after them. A "Burden of Illness" study creates a more comprehensive economic analysis incorporating such factors, and in principle could justify new treatments which a standard NICE analysis would reject as too expensive. At the March year end we had achieved the appropriate promises of funding but were still working on reaching agreement with an academic partner which would carry out the actual research. We are hopeful that we will finalise our negotiations and be able to go ahead in the third quarter of 2014.

We supported the work of the Penrose Enquiry and await its delayed publication. In Westminster, the Society acts as the Secretary to the All Party Parliamentary Group on Haemophilia and Contaminate Blood (APPG), and we have been working with the APPG to set up an inquiry through YouGov into the experiences of the beneficiaries of the Trusts and Foundations set up to support those affected by contaminated blood. We have also been supporting the important initiative led by Alistair Burt MP to bring full and final compensation following the contaminated blood tragedy.

We have begun initial planning for the 2018 Congress of the World Federation of Haemophilia in Glasgow, which The Haemophilia Society will host. This is a major international conference held every 2 years which is expected to attract over 6,000 clinicians, researchers, people affected by bleeding disorders, and other interested parties. The more focussed planning will begin in 2016 and we will need to attract capable volunteers to lead workstreams and to help on the ground. We will work with the UKHCDO and HNA in our planning for the event. We have also been involved in planning the Conference of the European Haemophilia Consortium which we will host in Belfast in October 2014.

Through our work, we encourage and advocate for everyone affected by a bleeding disorder to lead fulfilling lives, make informed choices and, through the Society and otherwise, to support and inspire others. We do this by providing accessible knowledge and support so that people can make their own informed decisions. We work to influence policy and practice so that the management, care and treatment for bleeding disorders is consistent, effective and accessible; and we enable the voices of those with bleeding disorders to be heard through our membership in NHS and other forums, and in the wider community.

We look forward to continuing and expanding this work, and to improving our communication with our members and stakeholders so that we can encourage greater participation in the Society's activities.

Liz Carroll  
Chief Executive, The Haemophilia Society  
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