

# BCSH Haemostasis and Thrombosis Task Force

## Membership

Dr D Keeling	Chairman
Dr H Watson	Secretary
Dr I Jennings	
Dr E Gray	NIBSC representative
Dr E Chalmers	
Prof M Laffan	
Dr A Mumford	
Dr C Tait	BSHT representative
Prof I Walker	NEQAS Representative
Prof M Makris	UKHCDO Representative - Up to April 2013
Dr Keith Gomez	UKHCDO Representative - Since May 2013

## UKHCDO guidelines published in association with the BCSH

Laffan M, Lester W, O'Donnell JS, Will A, Tait RC, Goodeve A, Millar CM, Keeling D. The diagnosis and management of von Willebrand disease: a guideline from the UK Haemophilia Centre Doctors Organisation. *British Journal of Haematology* 2014 (in press)

Collins PW et al. Diagnosis and treatment of factor VIII and IX inhibitors in congenital haemophilia. *British Journal of Haematology* 2013; 160:153-170

Collins PW et al. Diagnosis and management of acquired coagulation inhibitors: a guideline from UKHCDO. *British Journal of Haematology* 2013; 162: 758-773

## BCSH guidelines in development

Clinical genetics services for haemophilia

The treatment and prevention of bleeding in heritable platelet disorders

Patient based point of care testing for patients on vitamin K antagonists

Cancer and thrombosis

## UKHCDO relationship with BCSH Task Force

There is a well-defined pathway for guidelines of UKHCDO working parties to be published in collaboration with the BCSH. There are significant advantages in getting guidelines through the BCSH, not least of which is publication in a Wiley Blackwell journal – usually *British Journal of Haematology* or *Haemophilia*.

If any working party is intending to publish a guideline, they should contact Keith Gomez (the UKHCDO representative on the Task Force) at an early stage to get the production of the guideline approved under the BCSH methodology.

Professor Mike Makris  
July 2014

## 19. 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  
August 2014

## 20. The Macfarlane Trust

During 2013 and early 2014, the Trust experienced a number of changes of personnel – both Trustees and staff. Two long-standing Trustees, Elizabeth Boyd and Russell Mishcon, retired when their periods of office expired after more than 13 years and 7 years respectively. Kate Evans, a Trustee appointed on the recommendation of the Haemophilia Society, also resigned due to work and personal commitments. Three new Trustees were appointed: Jamie O'Hara was appointed by the Haemophilia Society to succeed Kate Evans, and the Trust also appointed Paul Biddle and Alasdair Murray, who bring experience in finance and policy to the board.

Following a Board-approved restructuring, Roz Riley, who had worked for the Trust since 2000, latterly as Support Services Manager, left in October 2013. Linda Haigh, Finance Manager, also left in January 2014 after 10 years in the organisation. The Trust has subsequently been pleased to welcome Victoria Prouse and Joyce Materego as the new Director of Operations and Director of Finance respectively.

In 2013/14 the majority of the Trust's annual budget continued to be used to make regular discretionary top-up payments to primary beneficiaries and regular payments to widows. The Board also agreed a cost of living increase to regular payments to primary beneficiaries of 2.7% for 2014/15. A winter fuel payment was made to primary beneficiary households in 2013/14, and a similar payment will be made in 2014/15.

In July 2013 the Board decided to commit funds from its reserves to support beneficiaries by funding improvements to their properties which were related to health and mobility needs. After inviting applications, the Trust allocated funds to 110 beneficiaries, totalling £811,000. This was a one-off exercise; we do not foresee monies being available in the future to do so again. We are confident that we have been able to make a significant positive impact on the lives of those beneficiaries who were awarded grants through this exercise. Many have expressed their appreciation through letters and emails to the Chief Executive and her team.

The Trust had partial success in 2013 regarding its negotiations with the Department of Health (DH) over its financial allocation for 2014/15. The Trust submitted a strong case for increasing its allocation from £2.2 million for 2013/14 to £3.2 million for 2014/15. This was always presenting a major challenge, given the state of the economy and general reductions in public spending. The DH agreed a figure which is, effectively, the same as the previous year. Bearing in mind the reductions being made elsewhere in public spending budgets, this was the best outcome we could have expected in the circumstances. The Board has agreed to continue supplementing the annual DH allocation from the reserve funds; this means that in 2014/15 we will be operating at a similar level to last year. However, the level of reserve funds is now reducing year on year and we are already having, reluctantly, to be discerning when deciding which grants we can fund. Unless the DH and government are able to increase the annual allocation to us, before long we will have no alternative but to review the feasibility of our current funding policies. It cannot be assumed that they will increase our budget. The Trust will, nevertheless, continue to press strongly for an increase in annual funding.

The Board is encouraged that the level of interest and awareness of national politicians has risen tremendously over the last year or so. This is in no small way attributable to a number of beneficiaries lobbying their MPs. There is, sometimes, a misunderstanding as to the responsibilities of MFT. These are confined to allocating regular funding to the beneficiary community and negotiating the best possible financial allocation from the DH to do so. Our responsibilities do not extend to lobbying for the wider interests and needs of the beneficiary community, even if sometimes we would like to do so. This is for others to do and the efforts of the beneficiary community, as recognised above, are invaluable in that respect.

Jan Barlow  
Chief Executive, Macfarlane Trust  
September 2014

## 21. Royal College of Physicians Clinical Effectiveness Forum

The Royal College of Physicians clinical Effectiveness forum meets semi-annually. During the last year, the main areas of discussion were around the following topics:

- The current status of the Future Hospital Programme
- Review of the national quality agenda, individual clinical outcome publication and open data & data sharing
- The role of guideline development and quality improvement
- The role of Health Quality Improvement Programme and quality improvement
- Evidence and quality improvement and the global concept of setting higher standards.
- Rationale and policy background to shared decision making and support for self-management as an approach to partnership working with patients and carers
- The key elements of shared decision making are patients and clinicians working together to select tests, treatments, management or support packages based on clinical evidence and patient preference
- Patients bring experience, personal values, knowledge and preferences, whereas clinicians bring best evidence presented clearly and skilfully
- Improved outcomes are the result of interaction between proactive prepared health team and informed activated patient
- A care plan is at the heart of a partnership approach to care and a central part of effective care management. The process of agreeing a care plan offers people active involvement in deciding, agreeing and owning how their condition is to be managed'
- The hours spent with healthcare professionals is a fraction of the time that patients with long term conditions spend in self-management
- Shared Decision Making (SDM) and Support for Self- Management (SSM) refer to a set of attitudes, roles, and skills, supported by tools and organisational systems, which put patients and carers into a full partnership relationship with clinicians in all clinical interactions. It was recognised that that patients and carers expect this to be the usual / default experience in their clinical interactions with Physicians and will work towards making this part of normal practice
- There was discussion that this practice and skills set needs to be woven into physician training and assessment, both undergraduate and post graduate as well as Consultant Physician training

Dr Bella Madan  
September 2014